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“They Did Not Know How to Talk to Us and It Seems That They Didn’t Care:” Narratives from Bereaved Family Members of Black Veterans

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Abstract

Racial disparities in the quality of health care services, including end of life (EOL) care, are well-documented. While several explanations for these inequities have been proposed, few studies have examined the underlying mechanisms. This paper presents the results of the qualitative phase of a concurrent mixed-methods study (QUANT + QUAL) that sought to identify explanations for observed racial differences in quality of EOL care ratings using the Department of Veterans Affairs Bereaved Family Survey (BFS). The objective of the qualitative phase of the study was to understand the specific experiences that contributed to an unfavorable overall EOL quality rating on the BFS among family members of Black Veterans. We used inductive thematic analysis to code BFS open-ended items associated with 165 Black Veterans whose family member rated the overall quality of care received by the Veteran in the last month of life as “poor” or “fair.” Four major themes emerged from the BFS narratives, including (1) Positive Aspects of Care, (2) Unmet Care Needs, (3) Lack of Empathy, Dignity, and Respect, and (4) Poor Communication. Additionally, some family members offered recommendations for care improvements. Our discussion includes integrated results from both our qualitative and previously reported quantitative findings that may serve as a foundation for future evidence-based interventions to improve the equitable delivery of high-quality EOL care.

Keywords Disparities · End of life · Veterans · Qualitative · Health equity

Background

Racial disparities in the quality of health care exist across the lifespan, including end of life (EOL) [1]. Marked differences between Black and White patients have been documented on a variety of EOL quality indicators, including bereaved family ratings of the quality of care [2–5]. In several studies, family members of Black decedents have reported significantly lower quality of EOL care compared to those of White decedents [6–8]. These differences extend to the Department of Veterans Affairs (VA), the nation’s largest integrated, equal-access health care system [9, 10]. In our recent national VA study, the percentage of bereaved family members who reported that the overall quality of EOL care received by the Veteran was “poor” or “fair” was nearly 1.5 times higher for Black Veterans compared to White Veterans (14.2 vs. 9.0%, respectively) [10]. While several explanations for these disparities have been proposed, such as poor communication with health care staff, medical mistrust, and receipt of more intensive EOL care among Black patients [5], few studies have been conducted to identify the mechanisms that underlie poorer ratings [6, 11]. Without understanding the drivers of racial disparities in EOL care quality, effective interventions to improve the delivery of equitable care remain elusive.

To address this gap, a concurrent mixed-methods (QUANT + QUAL) study of Veteran decedents and their bereaved family members sought to identify explanations for racial differences in quality of EOL care ratings using VA’s extensive clinical databases and Bereaved Family Survey

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(BFS). In the previously published quantitative phase of the study [10], we tested whether five EOL care processes, including receipt of intense EOL treatments, potentially burdensome transitions, and the three established BFS subscales of Respectful Care and Communication, Emotional and Spiritual Support, and Death Benefits, mediated the relationship between Black Veteran race and poorer BFS overall ratings. Even after accounting for a set of patient and facility characteristics, including receipt of palliative care, we found that the effects of the five EOL care processes combined accounted for only 5% of the observed racial differences in overall ratings. Thus, the addition of a qualitative approach provided an opportunity to expand the scope and breadth of our quantitative findings by allowing us to gain greater understanding about *why* families provided a “poor” or “fair” overall rating.

In this paper, we present the results of the qualitative phase of the study in which the open-ended BFS responses of family members of Black Veterans who reported an unfavorable overall EOL care experience were thematically analyzed. Our sample represented the 14.2% of all BFS responses from families of Black Veteran decedents who rated the overall quality of care as “poor” or “fair” in the quantitative phase of the study; in contrast, only 9.0% of families of White, non-Hispanic Veterans rated overall EOL care as “poor” or “fair” [10]. The purpose of this analysis was to understand the specific experiences that contributed to a “poor” or “fair” overall EOL quality rating among bereaved family members of Black Veterans, and to identify aspects of EOL care that are important to these families but are not currently elicited by the BFS. The paper also includes an integration of the study’s qualitative and previously reported quantitative findings and offers implications for future research and practice changes.

Methods

Design

We employed a qualitative descriptive design to analyze BFS open-ended items collected between October 2010 and September 2015. BFS data were merged with Veteran demographic and clinical data obtained from VA’s Clinical Data Warehouse (CDW) using a unique Veteran identifier. The 19-item BFS instrument is administered 4–6 weeks to the identified next-of-kin (NOK) of all Veterans who died in a VA inpatient setting via mail, phone, or online [12]. Among the items included on the BFS are two open-ended items, three psychometrically established subscales (Respectful Care and Communication, Emotional and Spiritual Support, and Death Benefits) [13], and a global rating of the overall quality of care received in the last 30 days of life. The BFS global rating was scored using a 5-point Likert scale with possible responses of “poor”, “fair”, “good”, “very good”, or “excellent”. The focus of the current analysis was on the two open-ended items that asked the NOK: (1) “Is there anything else that you would like to share about the Veterans care during his/her last month of life?” and (2) “Is there anything else that you would like to share about how the care could have been improved for the Veteran?” The survey response rate averaged 56% during the study period.

A key component of the concurrent mixed method design is integration. Integration can occur when the same sample is used for both the quantitative and qualitative phases and when results are provided from both approaches [14]. In this study, participants who completed the BFS for the quantitative study phase described elsewhere [10], also completed open-ended responses used in this study. In this sense, we achieved integration of methods by connecting the same sampling frames for the quantitative and qualitative questions. Integration of our findings was accomplished using the Pillar Integration Process outlined by Johnson and colleagues [15] and resulted in a joint display [16].

Sample

Our sample was derived from the 490 NOK of Veterans whose race was classified as “Black or African American” in CDW and died in a VA Medical Center acute or intensive care unit, and who rated the overall quality of care received by the Veteran in the last month of life as “poor” or “fair” in the quantitative phase of the study [10]. Of these 490 NOK, 165 provided a response to at least one of the two open-ended BFS items and were included in the final sample. Responses that were not substantive or detailed (e.g., “no”, “thank you”) were excluded. We focused our analysis on acute inpatient deaths because these settings may place minoritized Veterans at greatest risk for EOL care disparities [17].

Data Analysis

Characteristics of the Veterans and their NOK were described using basic descriptive statistics, including means and standard deviations for continuous variables and frequencies and percentages for categorical variables. We employed an inductive thematic content analysis to code the narrative BFS responses [18]. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to facilitate study rigor [19]. We also sought to establish trustworthiness using the hallmarks of qualitative research — credibility, transferability, dependability, and confirmability [20] — through strategies including developing a detailed audit trail, including responses from the NOK sample, and establishing interrater reliability [21, 22]. Two authors (KLR and MBC) each independently, then jointly, read and coded a sample of 30 responses to create a codebook which was iteratively refined. Next, the codebook was applied to the full sample of 165 BFS responses. Codes were systematically analyzed for patterns in the recurrence, distribution, and relationships of emergent concepts and categories, and were organized into themes and subthemes. Codes with higher numbers of associated quotes initially served as overarching themes, while fewer codes were organized under as subthemes. Themes and subthemes were then refined and collapsed based on their salience across responses. To support the dependability of our findings, each coder (KLR and MBC) independently and jointly coded 30% of the data and inter-rater reliability was established (kappa score = 0.85) [23]. The primary coder (KLR) coded 100% of the data to ensure internal consistency. Trustworthiness was maintained through weekly meetings where any discrepancies in interpretation, new codes, or changes in codes were reviewed. Finally, once themes and subthemes were identified, we reviewed them with an outside expert in EOL care to establish confirmability of our findings. NVivo 12 Plus (QSR International, Doncaster, Australia) was used for data management and analysis.

The Pillar Integration Process [15] was followed to produce a five-column, joint display of the integrated quantitative and qualitative results. This systematic technique consists of four stages: listing, matching, checking, and pillar building. We began by listing the results of the prior quantitative phase of the study (QUANT data column) [10], which included the portion of the total effect of Veteran race on an overall "poor" or "fair" rating that was attributed to each of the five tested EOL care process measures (i.e., % mediated effect). The overall quantitative findings were then thematically summarized in the QUANT categories column. Next, the qualitative subthemes (QUAL data column) and major themes (QUAL categories column) were listed and organized in a manner that matched with similar QUANT content horizontally in the display. Finally, the pillar building stage (Pillar Building Themes column) allowed for the identification of overarching themes, patterns, and shared areas of agreement (and disagreement) across data types.

Reflexivity Statement

We intentionally formed a study team composed of members with diverse backgrounds and expertise. Of the four investigators involved in the qualitative phase of the study, one was Black or African American and three were White. Our evaluation was informed by our expertise in qualitative research methods, mixed methods, end-of-life care, Veteran health care, and racial health inequities, as well as our diverse lived experiences. Study meetings included reflexive discussions of how our identities, experiences, and assumptions may have influenced our interpretation of the results.

Results

Characteristics of the Veteran decedents and BFS respondents included in the sample are presented in Table 1. The mean age of Veterans at the time of death was 67.8 years (standard deviation = 10.6). About half (44.9%) of BFS respondents identified themselves as the Veterans spouse. The top three most common primary diagnoses during the Veterans final admission were malignant neoplasm (19.4%), bacterial infection (13.9%), and heart disease (10.9%). On average, Veterans included in our sample had 8.6 comorbid health conditions as defined by Elixhauser and colleagues [24]. Over half (56.4%) of Veterans died in the intensive care unit while the remainder (43.6%) died on a medical/surgical unit. Over two-thirds (67.3%) of the Veterans in our sample died in a VA Medical Center located in the southern United States.

In our analysis of BFS narratives provided by family members who reported an overall "poor" or "fair" EOL care experience, four major themes emerged: (1) Positive Aspects of Care, (2) Unmet Care Needs, (3) Lack of Empathy, Dignity, and Respect, and (4) Poor Communication. Negative aspects of care (Themes 2–4) were shared more

Table 1 Sample characteristics of Veterans and corresponding BFS respondents ($n = 165$)

Age: mean (SD)	67.8 (10.6)
Next of kin relationship/ BFS respondent: n(%)	
Spouse	74 (44.9%)
Child	39 (23.6%)
Sibling	32 (19.4%)
Other	20 (12.1%)
Primary diagnosis (top 3 most common): n(%)	
Malignant neoplasm	32 (19.4%)
Bacterial infection	23 (13.9%)
Heart Disease	18 (10.9%)
Elixhauser comorbidity index: mean (SD)	8.6 (3.2)
Venue of death: n(%)	
Intensive care unit (ICU)	93 (56.4%)
Medical/surgical unit	72 (43.6%)
Region: n(%)	
Northeast	10 (6.1%)
Midwest	28 (17.0%)
South	111 (67.3%)
West	16 (9.7%)

Percentages may not add to 100 due to rounding. *BFS*, Bereaved Family Survey often than positive ones (Theme 1). The analysis also identified a set of recommendations for care improvements that arose largely from narratives describing negative aspects of care (Themes 2–4). Table 2 contains the 4 main themes, 13 subthemes, the number of BFS responses containing each subtheme, and exemplar quotes. An expanded set of representative quotes for each of the four themes and their subthemes are contained in Online Resources 1–4.

Table 2 Study themes and subthemes

Theme	*Subthemes*	*Number of BFS responses*	*Exemplar quote*
Positive Aspects of Care	Empathetic and Compassionate Care	17	"The aides, orderlies and their helpers were always kind, courteous, and helpful. If we asked for any updates or assistance for my husband, we always received it with a smile and a kind word."
	Effective Staff-Patient/Family Communication	6	"My husband's (she) doctors and nurses kept me informed of all the procedures necessary regarding the treatment of his ailment while he was in the hospital, with possible outcomes."
Unmet Care Needs	Inadequate basic care	60	"…I felt like my father did not receive even basic care. Many times he was unshaven and not bathed, still wearing the same stained gown from the previous day…."
	Delayed (not timely) care	46	"Often times the simple details of setting up his tray so he could feed himself was overlooked. He would tell me that it would take a long time for someone to come and change his diaper or reposition him."
	Veteran/family care wishes not honored	41	"When we decided to withdraw care, the doctors refused! This was very upsetting to our entire family. Not to mention Drs [Names] all became very aggressive with us after we decided to withdraw care. So aggressive that we had to end the conversation and leave the facility."
	Perceived harm from care	24	"He wasn't turned as often as he should have been or as scheduled. As the time of his death, he died with a stage 4 decubitus ulcer."
	Lack of trust in provider/staff competency	18	"In some cases, the nurse on duty would come into his room and provide medication and I would ask what is the medication for/and or treating? The nurse would reply, I'm not sure. You would have to consult the doctor."
	Unkempt facilities	13	"His room half of the time was dirty, floor covered with trash and trash can overflowing."
Lack of Empathy, Dignity, and Respect	Lack of empathy/poor bedside manner	49	"Doctors who took care of him they did not know how to talk to us and it seems like they didn't care."
	Lack of respect for Veterans	15	"From the time he was admitted to the time he passed I don't think or believe the care he received was the best or what as a Veteran he deserved."
Poor Communication	Patient status changes not communicated	55	"It was hit or miss if I would have any clue of where he even was, ICU or a room—once they moved him to a rehab center and no one told me."
	Lack of information about treatment and benefits	25	"They didn't tell us what to expect after his diagnosis…He had been exposed to agent orange. He was in stage 4 cancer. What does this mean."
	Fragmented healthcare team communication	12	"Talking to different doctors and getting different answers no one seemed to be on the same page."

BFS, Bereaved Family Survey

Positive Aspects of Care: "…With A Smile and a Kind Word"

While less common, several BFS respondents described positive aspects of the care experience in their narrative responses. The theme of Positive Aspects of Care encompassed aspects of the EOL care experience that were noted by families as positive or good, such as interactions with staff or specific care provision examples. The two subthemes were included: empathetic and compassionate care, and effective staff-patient/family communication.

Empathetic and Compassionate Care

Empathetic and Compassionate Care described examples of providers and staff displaying kindness, concern, caring, and support for the Veteran and family. Several family members referred to specific providers or staff members with gratitude while also expressing their trust and confidence in them. One family member stated "The aides, orderlies and their helpers were always kind, courteous, and helpful. If we asked for any updates or assistance for my husband, we always received it with a smile and a kind word." Additionally, some families noted these behaviors were more frequently experienced if the Veteran received palliative care services. For example, one family member wrote "On a more positive note, I would like to thank the Palliative Care team … all of whom consistently displayed professional and caring service to my husband. This was the team my husband had the most faith and trust in dealing with his care and concerns."

Effective Staff-Patient/Family Communication

Some BFS respondents also conveyed positive instances of effective communication. These narratives described examples of providers and staff who kept the Veteran and family informed of the plan of care, including honest assessments of possible outcomes. For example, one respondent noted "My husband's (she) doctors and nurses kept me informed of all the procedures necessary regarding the treatment of his ailment while he was in the hospital, with possible outcomes." Families also appreciated words and actions that showed respect for Veterans and their military service.

Unmet Care Needs: "I Believe He Should Have Been Monitored More Closely"

The theme of Unmet Care Needs referred to aspects of care that families expected for their Veteran family member near EOL but were not delivered in a timely manner or at all. Six subthemes were identified: inadequate basic care, delayed (not timely) care, Veteran/family care wishes not honored, perceived harm from care, lack of trust in provider/staff competency, and unkempt facilities.

Inadequate Basic Care

Failure to meet the basic care needs of the Veteran was a consistent sentiment expressed across BFS narrative responses for families reporting "poor" or "fair" overall care. Many family members reported that basic activities of daily living (ADLs) and related care were not appropriately provided by staff (e.g., bathing, shaving, poor positioning in bed, feeding). One family member wrote, "Many times he [the Veteran] was unshaven and not bathed, still wearing the same stained gown from the previous day…." Inadequate basic care also included situations where families noted that the Veteran was not monitored regularly or appropriately by staff. One BFS respondent noted, "My father aspirated while eating which led up to the complications that ended his life. He was a stroke sufferer and I believe he should have been monitored more closely during mealtimes."

Several family members reported stepping in to assist with providing basic care and unsuccessful attempts in advocating for the Veteran. One BFS respondent wrote that they "usually had to beg" staff to provide pain medication and suggested that the Veteran was not regularly assessed for pain. Another family member explained, "My father's speech was poor, and they did not take the time to understand his needs. I tried to speak for him, and they looked at me like I was making up his health issues."

Delayed (Not Timely) Care

Several family members reported that the Veteran did not receive care within a timely manner (e.g., delayed diagnosis, long wait for a specialist appointment, delayed receipt of pain medication). One family member wrote, "He would tell me that it would take a long time for someone to come and change his diaper or reposition him." In another example, a family member described delayed responses to the Veterans requests for help: "There were a few caregivers who were very attentive, however most of the evening caregivers very slow and sometimes unresponsive. He was crying in pain needing to go the bathroom…I'm not sure that he ever got help."

Veteran/Family Care Wishes Not Honored

Patient/family wishes for desired treatment sometimes diverged from the treatments recommended by health care providers and staff. In some cases, these situations lead to the receipt of inappropriate care or care decisions by providers that went against the expressed wishes of the Veteran and/or family. Families described instances of providers trying to convince the Veteran and/or family to agree with their plan to pursue or discontinue treatment. One BFS respondent described the following situation: “Mr. [Name] chose to be resuscitated if his heart stopped during his stay/illness but numerous times during the stay the patient and his family were asked to ‘Just let God have His way.’ Please adhere to the patient’s and family’s wishes because this type [of] scenario validates the problems of disparity in the care of minorities in America.”

Perceived Harm from Care

Some bereaved family members reported that Veterans were hurt or that their death was related to provided or omitted care. One family member wrote “He wasn’t turned as often as he should have been or as scheduled. At the time of his death, he died with a stage 4 decubitus ulcer.” In another BFS response, the child of a Veteran wrote “My dad had had a temperature earlier on the day he passed when I was visiting. The nurse just gave him Tylenol and dismissed the symptom. I even asked if it could be a UTI [urinary tract infection]. My dad passed from sepsis. So many times, I questioned the cleanliness of equipment and his being turned…it's too late for my dad but there are others experiencing the same. Do something…make unannounced after 5PM inspections…send secret shoppers…someone's life depends on YOU! Quality should not be an option!”.

Lack of Trust in Provider/Staff Competency

Other narratives were directed towards staff that were perceived to not take their job seriously, or as lacking knowledge, experience, training, or education, particularly related to the delivery of EOL care. One BFS respondent noted that “The new doctor knew nothing about taking care of the dying. It is sickly.” In another example, a family member described a scenario where “the nurse on duty would come into his room and provide medication and I would ask ‘what is the medication for/and or treating?’ The nurse would reply, ‘I’m not sure. You would have to consult the doctor’.”

Unkempt Facilities

A few comments described unsanitary or uncomfortable rooms for Veterans in which care was provided and was often attributed to staff not doing their jobs. One family member stated that “His room half of the time was dirty, floor covered with trash and trash can overflowing.”

Lack of Empathy, Dignity, and Respect: “They Did Not Know How to Talk to Us and It Seems Like They Didn’t Care”

The theme of Lack of Empathy, Dignity, and Respect described instances in which the actions and attitudes of providers/staff did not convey emotional support or respect to Veterans near EOL and to their families. Two subthemes were lack of empathy/poor bedside manner and lack of respect for Veterans.

Lack of Empathy/Poor Bedside Manner

Many BFS respondents who gave an unfavorable overall rating of EOL care described a lack of empathy and compassion from providers and staff towards the Veteran and/or family. Families described negative experiences with providers and staff who displayed poor bedside manner that reflected rudeness, cold attitudes, and inadequate listening skills (e.g., staff did not introduce themselves, lack of privacy, hurried conversations). Many respondents recounted interactions that did not express kindness, caring, or support. One family member noted that “Doctors who took care of him they did not know how to talk to us, and it seems like they didn’t care.”

Lack of Respect for Veterans

Family members described disrespectful attitudes and actions, that were perceived as rude and indicative of a lack of respect for Veterans. Several respondents felt that the Veteran deserved better care, particularly at EOL, given the sacrifice that the Veteran made in terms of military service. One BFS respondent wrote “From the time he [the Veteran] was admitted to the time he passed I don't think or believe the care he received was the best or what as a Veteran he deserved.”

Poor Communication: “No One Seemed to Be on the Same Page”

The theme of Poor Communication included descriptions of gaps in communication about the Veterans care that occurred between and among Veterans, families, and health care staff/providers across the EOL care continuum. Three subthemes were patient status changes not communicated, lack of information about treatment and benefits, and fragmented health care team communication.

Patient Status Changes Not Communicated

Many bereaved family members described situations when the Veteran and/or family was not told (or not told in a timely manner) about a change in patient status (e.g., prognosis) or their care (e.g., unit change). In some instances, this lack of communication led to missed opportunities for the family to be present with the Veteran in the way that they had wanted. One family member recounted “My youngest daughter [name] gave the staff at the hospital our updated phone numbers, but it was never put into the system … we were never notified that he was going into surgery before he died. We feel we were robbed of the opportunity to speak with him…We couldn’t even pray for him because we did not know he was going into surgery…”.

Lack of Information About Treatment and Benefits

Some BFS respondents reported that they were not provided information or clear explanations about the Veterans condition and treatment (e.g., surgery risks). For example, one family member stated that “They [providers/staff] didn’t tell us what to expect after his diagnosis…He had been exposed to Agent Orange. He was in stage 4 cancer. What does this mean?” Other respondents reported not receiving VA burial and memorial benefit information (or not receiving them in a timely manner) and expressed frustration with not being made aware of the expected timeframe to obtain them.

Fragmented Health Care Team Communication

A few bereaved family members also perceived a lack of communication between members of the Veterans health care team. These communication gaps sometimes resulted in a lack of care coordination and a lack of provider and family knowledge about the Veterans status (e.g., may not know the Veteran has been hospitalized). One BFS respondent expressed that they were “Talking to different doctors and getting different answers no one seemed to be on the same page.”

Recommendations for Care Improvements

Recommendations for care improvements were identified in BFS responses (largely in relation to negative aspects of care) that included a suggestion(s) about how to improve care for the Veteran and/or family. Recommendations were broadly organized into four categories related to: Care Provision, Veteran/Family-Staff Relationships, Staffing and Human Resources, and Support Services (see Fig. 1). The Care Provision category included suggestions related to the improving the care delivery process, such as ensuring access to necessary care (e.g., specialist appointments, hospital bed availability), and ensuring that Veterans basic care needs are met, including bathing and maintenance of patient privacy. The category of Veteran/Family-Staff Relationships included the most frequently mentioned recommendations, including taking time to talk with and listen to patients and families. More specifically, family members suggested improvements in information sharing (e.g., prognosis) and limiting the use of medical jargon particularly when discussing EOL care. This category also included other common recommendations including the employment of staff who are caring, and who are experienced/well-trained. Family members recommended hiring staff who are competent in caring behaviors and communication skills, and training existing staff in these areas if necessary. The category of Staffing and Human Resources encompassed family-driven recommendations such as increasing staffing levels, particularly for nurses, which some families perceived to be inadequate for the delivery of Veterans care. Several families also suggested discharging providers and staff that provide poor care (based on more direct monitoring of providers/staff to ensure good care). The Support Services category included suggestions related to VA benefits and other support programs for Veterans and their families. Examples of recommendations in this category included providing timely benefit information/assistance and timelines to patient/family and connecting Veterans and families to a patient care representative that could assist with issue resolution.

Discussion

In our examination of BFS narrative responses from family members of Black Veterans who rated the overall quality of EOL care as “poor” or “fair”, we found descriptions of a care experience that often-lacked essential basic care, empathy and respect, and effective communication. Although these comments come from a subset of all families of Black Veteran decedents, they are concerning as they lay in stark contrast to VA’s core values of Integrity, Commitment, Advocacy, Respect, and Excellence (I CARE) that are pledged by VA employees every year [25]. Our results offer recommendations informed by bereaved family members of Veterans that may be used to inform immediate and future efforts to improve the delivery of culturally humble, high-quality EOL care. As part of a larger mixed-methods study to understand the drivers of racial disparities in EOL care quality ratings, this qualitative analysis served to confirm, disconfirm, and expand our quantitative findings as illuminated by our joint display (Table 3).

Pillar Building Theme 1: Insufficiency of Current BFS Items to Measure Factors Associated with EOL Care Quality Ratings Among Families of Black Veterans

One pillar theme that emerged from the integrated results was the insufficiency of current BFS items to measure factors associated with EOL care quality ratings among families of Black Veterans. Sentiments related to unmet care needs and poor communication were commonly expressed in the

Fig. 1 Recommendations for improvement. Note: Number of Bereaved Family Survey (BFS) responses in parentheses

Care Provision

- Diagnose patient earlier (3)
- Improve treatments (e.g. better medication) (3)
- Earlier patient transfer to appropriate care/provider (e.g. specialist care) (2)
- Ensure access to care (e.g. available hospital bed) (2)
- Improve basic care provision (1)
- Better privacy practices for patient (e.g. when bathing/changing clothing) (1)
- Improve cleanliness of hospital rooms (e.g. provide more sanitation) (1)
- Ensure equipment working properly (e.g. call button) (1)

Veteran/Family-Staff Relationships

- Take time to talk with/listen to patient/family (14)
- Have caring staff (13)
- Have experienced/well-trained providers/staff (11)
- Pay more attention to patient/provide more "hands-on" assistance (so staff meet patient needs) (6)
- Address patient/family feedback on care provision (5)
- Respect for Veteran patients from providers/staff (5)
- Have providers that patient/family knows/trusts to provide care (2)
- Discuss possible treatments with patient/family before (not) given (2)
- Clarify provider/staff roles to patient/family (1)
- Match sex of staff and patient for certain care (e.g. clothing changes) (1)
- Match language of staff and patient (1)

Staffing and Human Resources

- Discharge providers/staff who provide poor care (7)
- Increase staffing (6)
- Increase provider/staff supervision (4)
- Increase availability of providers/staff (1)

Support Services

- Provide timely benefit information/assistance and timelines to patient/family (3)
- Have someone available who can help patient/family with issue resolution (3)
- Hold timely Veteran-related services (2)
- Make peer support available to Veterans (1)

BFS open-ended responses by bereaved family members of Black Veterans who rated the overall care as “poor” or “fair.” Among the BFS quantitative measures is the Respectful Care and Communication subscale — which includes items such as whether the Veterans personal care needs were met, staff kept family informed, and the Veteran received desired treatment. While these subscale items directly map onto several of the qualitative subthemes related to care and communication identified in the current study, our findings were not confirmed by our prior quantitative mediation analysis [10]. The Respectful Care and Communication subscale did not statistically explain any of the relationship between Black Veteran race and poor BFS overall ratings. Thus, it is possible that examining these complex, interpersonal relationships using a BFS subscale may not have captured the full experience of Veterans and their families related to these core aspects of EOL care.

In contrast, the qualitative subthemes revealed more nuanced descriptions of experiences within the domains of care and communication that were clearly important to families but not measured on the BFS. For example, several comments were related to delayed care, perceived harm from care, and staff-family disconnection about care goals. Open-ended responses related to experiences of delayed care involved situations ranging from being unable to access specialty care when an appointment was needed, to being cared for in facilities where staff were unable to attend to patient care needs in a timely way. Some family members of Black Veterans perceived that the Veteran was harmed as result of provided or omitted care. We noted in some of these instances that while the actions of the providers/staff may have been clinically appropriate for patients nearing EOL (e.g., treating symptoms but not the underlying etiology), family members viewed the care as harmful and inappropriate in the absence of a clear and understandable explanation. Some bereaved families of Black Veterans who reported “poor” or “fair” overall care also reported experiencing open conflict with providers/staff about the Veterans treatment wishes that caused distress, particularly when the respondent felt that the staff was being dismissive and disrespectful of the Veterans and/or family’s choices. These experiences may represent examples of racial microaggressions and implicit bias [26, 27] although these are not currently queried on the BFS or on other large patient/family experience of care surveys, including the Centers for

Table 3 Pillar integration of mixed methods results

QUANT Data [10]	QUANT Categories	PILLAR BUILDING THEMES	QUAL Categories	QUAL Data
Care and Communication (BFS subscale): % mediated effect= -0.8%	BFS items related to Care and Communication (5 items, i.e., staff listened to concerns, staff provided medical treatment that the Veteran wanted; staff were kind, caring, and respectful; staff attended to personal care needs) explained none of the relationship between Black Veteran race and a poor/fair BFS overall rating.	Insufficiency of current BFS items to measure factors associated with quality of EOL care ratings among Black Veterans and families	Unmet care needs	-Inadequate basic care -Delayed care -Veteran/family care wishes not honored -Harm from care -Lack of trust in provider/staff competency -Unkempt facilities
			Poor Communication	-Patient status changes not communicated -Lack of information about treatment and benefits -Fragmented healthcare team communication
Emotional and Spiritual Support (BFS subscale): % mediated effect=3.5%	BFS items related to Emotional and Spiritual Support (3 items, i.e., staff gave enough emotional support before death; staff gave enough emotional support after death; staff gave enough spiritual support) explained a small amount of the disparity.	Unmet emotional care needs	Lack of empathy, dignity and respect	-Lack of empathy/poor bedside manner -Lack of respect for Veterans
Death Benefits (BFS subscale): % mediated effect=1.7%	BFS items related to receipt of death benefit information (3 items, i.e., staff gave enough information about survivor's benefits; staff gave enough information about burial and memorial benefits; staff gave enough help with funeral arrangements) explained a very small amount of the disparity.		Not identified	
Potentially burdensome transitions: Not statistically significant High-intensity EOL treatment: % mediated effect = 0.1%	Receipt of high-intensity treatment and experiencing multiple transitions near end of life explained none of the disparity.	Reconceptualize the use of "burdensome" transitions and "aggressive" EOL treatments in the evaluation of quality of EOL care among minoritized patient populations	Not identified	

Quant data and categories were published previously [10]. Data in QUANT data column reflects the % of the relationship between Black Veteran race and a poor/fair BFS overall rating that was explained by each tested mediator variable. A potentially burdensome transition was defined as either: 1) the Veteran's final hospital admission (during which the patient died) occurred three or fewer days prior to death, or 2) the Veteran was hospitalized three or more times during the last 90 days of life. High-intensity EOL treatment was defined as receipt of cardiopulmonary resuscitation and/or mechanical ventilation within the last week of life followed by death in the intensive care unit (ICU)

Medicare and Medicaid Services (CMS) Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys. Indeed, several recent studies suggest that Black patients are more likely than White patients to report experiencing racial discrimination during health care encounters [28–30].

Pillar Building Theme 2: Unmet Emotional Care Needs

The lack of empathy and poor bedside manner displayed by providers and staff were among the most frequently mentioned experiences of families of Black Veteran decedents who reported "poor" or "fair" overall care at EOL. In the quantitative phase of the larger study using the same sample of BFS respondents, we found that the BFS subscale of Emotional and Spiritual Support emerged as the strongest of five EOL care processes that were tested as potential mediators of the relationship between Black Veteran race and lower BFS overall ratings [10]. Although the statistical mediation effects were not large, this consistent finding across both data types resulted in unmet emotional care needs being identified as a second pillar theme of our integrated findings. The demonstration of empathy, compassion, and physical presence by health care staff is highly valued by patients near EOL and their families [31, 32]; however, as shown in our work and others', Black patients and their families are less likely than their White counterparts to report receiving these demonstrations of support [9, 10, 33, 34]. Notably, we observed that demonstrations of empathetic and compassionate rapport with patients and families, as well as taking time to listen and understand their needs, were among the most frequently mentioned positive aspects of care and recommendations for improvement among family members of Black Veterans. Taken together, our results indicate that unmet emotional care needs are one of the drivers of racial disparities in overall ratings of the quality of EOL care and could be the focus of quality improvement initiatives.

The themes and subthemes that emerged from our qualitative analysis strongly align with a growing literature base that names racism and its various forms — structural, institutional, and interpersonal [26] — as a major cause of health care disparities [35], including care at EOL [1, 4, 5, 36–38]. Although we were not able to directly ask BFS respondents about experiences of racism, the responses to the BFS open-ended items conveyed numerous examples of "inaction in the face of need" [26] in the last month of the Veterans life at the physical, emotional, and health care system-levels. Thus, together with our quantitative findings that largely left the disparity in overall ratings unexplained, our findings suggest that a combination of the various forms of racism may be contributing to observed racial disparities in EOL care quality and should be directly assessed in future work.

Pillar Building Theme 3: Reconceptualize the Use of "Burdensome" Transitions and "Aggressive" EOL Treatments in the Evaluation of Quality of EOL Care Among Minoritized Patient Populations

Ensuring that we are measuring aspects of EOL care quality that resonate with racialized communities will be essential to creating effective patient-centered interventions and measuring progress. This recommendation is supported by our third and final pillar theme identified from the integration of our findings: the need to reconceptualize the use of "burdensome" transitions and "aggressive" EOL treatments as indicators of poor EOL care quality among Black patients. While these measures have been utilized frequently in the literature as indicators of poor quality of EOL care [2, 39, 40], we found no evidence in our quantitative and qualitative analyses that additional care utilization or treatments near EOL by Black Veterans contribute to racial disparities in bereaved families' overall ratings of care. Further, use of labeling terms, such as "burdensome" and "aggressive" in the context of EOL care discussions with socially minoritized patients and their families acts as a barrier to allowing the patient's goals, values, and preferences to guide EOL care [41].

Further, specific items about experiences of racism, discrimination, and microaggressions should be integrated into patient/family experience of care surveys, including those evaluating quality of EOL care. Additional qualitative and community-based participatory studies of Black Veterans and their family members that allow for more in-depth exploration of their experiences with racism and the elements of EOL care that are most important to them are needed [42]. All frontline clinicians and staff, including those that provide EOL care, should participate in required continuing education about diversity, equity, and inclusion [DEI] topics, including the recognition and management of implicit bias and strategies for how to reduce and eliminate discriminatory behavior [43]. Research is also warranted to understand whether disparities in EOL quality are equally present across VA facilities which would provide greater insight into how institutional policies, DEI initiatives, and resource allocation affect care delivery to minoritized groups. Valuable lessons may be learned from facilities that have achieved equity in EOL care quality ratings. Ultimately, interventions developed in partnership with Black Veterans and their families are needed to effectively "move the needle" in reducing and eliminating racial disparities in quality of EOL care.

Study Limitations

The study findings should be interpreted in the context of some limitations. First, answering the quantitative BFS items may have "primed" respondents to focus on those specific areas in their responses to the open-ended items. Primary data collection using interviews would allow for greater exploration and probing of responses. Second, our study partially pre-dates the creation of VA's Office of Health Equity in 2012. Two years later, this office issued the first version of a living action plan that is used to guide VA's activities for improvement in five focus areas, such as increasing awareness of the significance of disparities and strengthening leadership for addressing them [44]. Therefore, improvements may have occurred since that time. Third, our findings focus solely on the experiences reported by bereaved family members of Black Veterans. It is possible that family members of Veterans from other racial and ethnic groups may have similar or different experiences. Finally, our qualitative sample ($n = 165$) was comprised of approximately one-third of respondents included in the quantitative phase of the study ($n = 490$), and thus may not be representative of family members of Black Veterans who gave an overall "poor" or "fair" rating; however, the demographic and clinical characteristics of the two samples are similar [10].

Conclusion

As part of VA's comprehensive action plan to address President Biden's Executive Order, "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government" [45], the Veterans Health Administration has committed to the inclusion of equity in quality improvement and performance monitoring processes by tracking disparities in outcomes and to conducting more human-centered design research to better understand the needs and preferences of minoritized Veterans and their families [46]. As such, our findings, including the experiences and recommendations of bereaved family members of Veterans, can be used to tailor the BFS and other instruments measuring quality of EOL care and serve as a foundation for evidence-based interventions to improve the equitable delivery of high-quality EOL care.

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Declarations

Ethics Approval Human subjects' approval for this secondary analysis was received from the Corporal Michael J. Crescenz VA Medical Center Institutional Review Board, Philadelphia, PA, USA, and the VA Pittsburgh Healthcare System Institutional Review Board, Pittsburgh, PA, USA.

Conflict of Interest The authors declare no competing interests.

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