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ORIGINAL ARTICLE

The experience of providing hospice care concurrent with cancer treatment in the VA

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Abstract

Purpose Veterans with advanced cancer can receive hospice care concurrently with treatments such as radiation and chemotherapy. However, variations exist in concurrent care use across Veterans Affairs (VA) medical centers (VAMCs), and overall, concurrent care use is relatively rare. In this qualitative study, we aimed to identify, describe, and explain factors that influence the provision of concurrent cancer care (defined as chemotherapy or radiation treatments provided with hospice) for veterans with terminal cancer.

Methods From August 2015 to April 2016, we conducted six site visits and interviewed 76 clinicians and staff at six VA sites and their contracted community hospices, including community hospices ($n = 16$); VA oncology ($n = 25$); VA palliative care ($n = 17$); and VA inpatient hospice and palliative care units ($n = 18$).

Results Thematic qualitative content analysis found three themes that influenced the provision of concurrent care: (1) clinicians and staff at community hospices and at VAs viewed concurrent care as a viable care option, as it preserved hope and relationships while patient goals are clarified during transitions to hospice; and (2) the presence of dedicated liaisons facilitated care coordination and education about concurrent care; however, (3) clinicians and staff concerns about Medicare guideline compliance hindered use of concurrent care.

Conclusions While concurrent care is used by a small number of veterans with advanced cancer, VA staff valued having the option available and as a bridge to hospice. Hospice staff felt concurrent care improved care coordination with VAMCs, but use may be tempered due to concerns related to Medicare compliance.

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Introduction

The "terrible choice" [1–4] refers to the decision Medicare beneficiaries with advanced cancer make between hospice care and continued receipt of chemotherapy and/or radiation [5, 6]. However, veterans receiving care through U.S. Veterans Health Administration (VA) can receive these treatments in addition to VA facility-based hospice care and community hospice services, concurrently. VA benefit allows concurrent care, provided services are not duplicated, and care is coordinated between hospice and VA. Recent research demonstrates an increase in concurrent care among veterans with advanced cancer, largely driven by expanding hospice services within VA [7]. However, data on concurrent care is sparse because, outside of VA, there is virtually no consistent opportunity to receive it except for the Medicare Care Choices Model [8] which is only in a demonstration phase [9].

One of the few studies published on concurrent care surveyed 198 adult smokers asking them to imagine having advanced lung cancer and rate treatment preferences. Forty-two percent chose concurrent chemotherapy and hospice (10% chose supportive care only; 19% hospice only; and 29% chemotherapy only) [10]. Studies have documented clinical benefits [11] and cost utility of radiation [12] and chemotherapy [13, 14] in advanced lung cancer, and note these therapies are most effective when accompanied by expert symptom management. Hospice care in lung cancer patients is known to improve symptom management and end-of-life outcomes [15, 16]. However, the majority of veterans (53%) with advanced lung cancer do not enroll in hospice until the last month of life [17]. In another study interviewing non-veteran families and patients about reasons for declining hospice [18], participants cited the following: requiring patients/families to choose between hospice or palliative treatments; hospices' focus on what *is not* provided; and concerns about continuity of care, including losing their current provider after hospice enrollment.

These studies raise important questions about concurrent care, indicating a desire for it and potentially better outcomes when receiving it, yet in VA, where it is allowed, it happens rarely. There is a need to better understand how care is coordinated and provided across multiple settings and clinicians, especially as no standardized model of care coordination exists. This lack of standardization occurs because payment and regulatory policies discourage concurrent care, and in most cases, oncologists refer patients to hospice when they stop chemotherapy/radiation. Additionally, patients find traveling to office visits difficult as diseases progress and functional status declines. It is unknown what barriers might arise related to regulatory or fiscal issues. To date, debate about concurrent care has either been hypothetical or focused on individuals' preferences but uninformed by data.

Study aims

Considering high incidence of cancer in veteran and U.S. populations [19–23], the increasing trend towards concurrent care [7], and possible changes in Medicare policy depending upon results of the Medicare Care Choices Model [8], an understanding of concurrent care processes in VA is critical to better serve veterans and to understand reasons for its scarcity in a system that allows concurrent care. To address these issues, we conducted a qualitative study, interviewing clinicians and staff at Veterans Affairs Medical Centers (VAMCs) and community hospices across the USA. This work is part of a larger national, mixed-methods study designed to understand trends, costs, and benefits of concurrent care for veterans [24, 25].

Theoretical framework

Our work was informed by the theory of relational coordination [26]. The theory considers the roles frequent, timely, accurate, and problem-solving communication plays in coordination processes (in this research, provision of concurrent care) and considers if relationships are characterized by shared goals, shared knowledge, and mutual respect. While research applying relational coordination theory has often focused on coordination across teams within organizations [27, 28], this study focuses on care coordination across organizations (VAMCs and community hospices). Prior research describing coordination between nursing homes and hospices suggests that extension of this theory is appropriate [29–31].

Methods

Design and sample

We applied a sequential, multilevel, explanatory design [32] for this study (quantitative data from the larger national study informed site selection). Site selection criteria included proportion of veterans receiving concurrent care (stratified as low, medium, and high levels) provided at each VAMC based on VA data collected between 2007 and 2012. We sought to identify a sample of participants based on maximum variation across sites [33]. We identified 15 eligible sites and chose six based on the presence or lack of an inpatient hospice palliative care unit (HPCU) and geographic variability. The investigative team visited two sites from each stratum (low,

medium, and high concurrent care), and five had HPCUs. All six sites agreed to participate.

We conducted semi-structured in-person individual and small group interviews with VA clinicians and staff from palliative care, oncology, HPCUs, and non-VA hospices. We used snowball sampling techniques [34], identifying participants through contacts with oncology, palliative care, and hospice leadership. We interviewed $n = 76$ participants from the following: community hospices ($n = 16$); VA oncology departments ($n = 25$); VA palliative care teams ($n = 17$); and VA HPCUs ($n = 18$). Table 1 shows a breakdown of participants by role. All participants participated voluntarily, without incentives, and completed informed consent documents. VA Central Institutional Review Board (CIRB #13-03) approved the study.

Data collection

Two to three members of the research team conducted site visits spanning two-to-three days: a geriatrician clinician-researcher who is board-certified in hospice and palliative medicine; a licensed clinical social worker; and a health research specialist with doctoral training. Rapport with staff, fostered thorough planning, and a detailed interview schedule ensured access to participants. Semi-structured interview guides facilitated a balance of open-ended questions while focusing on concurrent care provision (Electronic Supplementary Materials). We refined interview guides iteratively during data collection [35, 36] and recorded interviews, which ranged from 17 to 71 min (mean duration = 44 min).

Data analysis

Our team-based, general inductive approach to thematic content analysis employed a dynamic and iterative interplay of inductive (letting new codes emerge) and deductive (incorporating previous knowledge and frameworks) analytic strategies [37–39]. We created a priori codes based on keywords extracted from interview guides and included additional in vivo codes that emerged as data were analyzed line-by-line. Memos describing emerging themes and unique observations were generated while coding. This commenced at the first interview and continued throughout data collection. Consensus building occurred during regularly scheduled team meetings and discussions over several months, allowing themes to materialize and fully develop. A professional transcription service transcribed interviews verbatim, and three research team members analyzed data using Atlas.ti V7.5.2 data management software [40].

Results

Findings from interviews revealed three themes reflecting two facilitators and one barrier to provision of concurrent care. The two facilitators are concurrent care preserves hope and relationships during transitions to hospice, and dedicated VAMC-based liaisons are needed to coordinate care and educate community hospices on concurrent care. The third theme, representing a potential barrier, is concern over compliance with Medicare hospice regulations. Results are reported as an aggregate of descriptive themes that influenced provision of concurrent care.

Concurrent care preserves hope and relationships during transitions to hospice

Hospice and VA clinicians perceived adding hospice to their veteran cancer patients' care plans as valuable. Clinicians described hospice services as improving quality of life for veterans because of expert symptom management and increasing a sense of health security for veterans due to frequent home visits from hospice staff. In some cases, staff provided veterans their phone numbers, lowering veterans' potential to call emergency rooms. Participants described that concurrent care preserved continuity with veterans' VA cancer-care clinicians. An oncologist explained, "If I think somebody has a life expectancy of a year or less and the cancer is not curable then I put a hospice consult in and explain to the patient that hospice never takes, it only gives, and I found that it's very useful." For veterans who wanted to continue chemotherapy/radiation but equated hospice with "giving up" and "losing hope," these clinicians found simultaneously providing hospice and chemotherapy/radiation preserved hope. This allowed for a

Table 1 Interview participants by role and group

	VA Oncology	VA Palliative Care	Community Hospice	Hospice Palliative Care Units	
Physicians	10	4	12	4	
Nurse practitioners	2	10	0	5	
Nurses	8	0	2	5	
Social workers	4	3	0	4	
Other staff	1	0	2	0	Total
Total Participants	25	17	16	18	76

gradual transition to treatments aimed at comfort as families and veterans assessed benefits and burdens of chemotherapy/radiation.

Participants described concurrent care as a means of honoring care that patients valued, with one palliative care nurse practitioner (NP) noting, "I think that, for me, [this] was a breath of fresh air here having to provide that kind of [concurrent] care without the need to have the patient decide to, you know, forego the treatment they felt was very important to them." Participants perceived concurrent care as a more humane approach to care, while veterans and families considered effects of chemotherapy/radiation on quality of life. One hospice provider shared,

> When you're able to say you're still able to do palliative treatments, you know, we're not going to cure but we're going to help…it's like you're not…not just slamming the door and saying, 'We're giving up on you.' It's saying, as far as aggressive treatment, there's nothing else we can do but we do realize the pain level, [and] we're going to shrink this tumor…And as long as the quality of life is there I think that it [concurrent care] should be done.

A VA palliative care NP shared that concurrent care preserved relationships with current clinicians and eased transitions to hospice services. She contrasted this experience with her previous job as a community hospice admissions nurse where patients had to abruptly sever relationships with long-term clinicians to enroll in hospice, which became a barrier to hospice enrollment. Another VA oncology NP added that "most of the people that we're talking about that are getting concurrent chemotherapy still want to feel like they can access us [VA] when they need to." Participants described that they continued to manage overall care of veterans when they were admitted to hospice, with one oncologist adding that co-managing with hospice "Very, very, very good when I co-manage a patient at least from my experience they're [hospice] always around. The patient can depend on them." Another VA oncology/palliative care physician shared being very conscious of veterans' potential to feel abandoned when transitioning to hospice, so they chose to remain as their provider.

Dedicated VAMC-based liaisons are needed to coordinate care and educate hospices on concurrent care

Participants described benefits of having dedicated liaisons to facilitate delivery of concurrent care and educate hospices. Often, these were nurse managers, oncologists, or palliative care physicians and became points of contact for hospices. While hospices generally assumed provided primary care for veterans, ordering medications, and managing symptoms, complex care needs required coordination for scheduling outpatient cancer therapies and communicating during hospitalizations. One hospice nurse noted, "We have had some incredible nurse liaisons at the VA to call, and they would actually answer the phone and they were fairly knowledgeable. They were very helpful on how we should proceed."

When a physician served as a liaison between hospice and VAMCs, this facilitated provision of concurrent care and created a culture in which hospices directly contacted them with questions. One hospice nurse noted,

> [VA doctor's name] wants me to call him every Monday, every week when I see the patient and you know, he's very open. I keep saying 'Are you sure you want me to call you?' He said, 'Oh yeah, give me a call.' You know, that's wonderful, and the patients—the patient is the one who gave me his phone number.

One VA palliative care NP shared that if hospices had questions about medication management, hospices contacted her for clarification. Hospices embracing concurrent care for veterans shared many examples of co-managing duties between themselves and VA clinicians. One hospice physician shared that:

> Generally, with concurrent care, there is one facet of the care that [the VA] is taking care of rather, it's oncology or radiation… we [hospice] take care of the rest. It's agreed-upon that we're [hospice] going to manage the case—the pain, the dyspnea, the issues with psychiatric problems. We manage most of that stuff. And if there are problems, you know, that is when we tried to contact the referring doctor.

When veterans receiving concurrent care were admitted to the hospital, participants described care plan management as complex. During hospitalization of a hospice patient, a hospice provider said they struggled with coordinating care,

> If you're in hospice one of the rules is if they [Veterans] get admitted to the hospital you have to be able to coordinate the care. None of our [hospice] nurses in there are licensed to go in there [VAMC]… So that's always been one of our struggles around that regulation of we have to be responsible for coordinating the care.

Despite complexity of coordinating care when veterans are hospitalized, two hospice physicians explained that if a veteran is admitted to the hospital, their hospice policy is to determine after 24–48 h severity of veteran's needs; if deemed less severe, hospice would absorb the veteran back. One VA palliative care nurse manager explained that efforts to coordinate

care improved over time when veterans were hospitalized and receiving concurrent care.

> We're finding that the more we've worked with them [hospices] the more they've recognized that okay this is… a procedure that they [Veterans] can benefit [from] in the hospital to improve their quality of life and their pain control. And we actually have [hospices] help us admit to the hospital or to the clinic to come up for care.

Concern over compliance with Medicare hospice regulations

Hospice and VA participants had varied interpretations of Medicare guidelines regarding provision of concurrent care. Hospices shared pervasive concerns over the responsibility of payment for chemotherapy/radiation. Some participants thought veterans' pursuit of chemotherapy /radiation, even with palliative intent, was misaligned with hospice philosophy. One VA oncologist said, "The only pushback we get is from the hospice itself because they want the patient to only be in a palliative mode and so we've got to convince them that yes this treatment is for palliation it's not for active treatment."[1]

Some hospice clinicians permitted concurrent care if intent was palliative, regardless of Medicare or VA paying, but described needing to consider overall costs when patients chose to continue chemotherapy/radiation, which can be costly. These hospices tended to have larger censuses, allowing for more financial margin in providing expensive treatments. One hospice administrator estimated that approximately 35–45% of families (veteran and non-veteran) would decline hospice if concurrent care were not permitted. "When I say, 'Yes this is what we can do,' you hear that sigh of relief and saying, 'Thank God.' You know, it's 'yes we are able to do this, yes we're able to do that.' Sometimes it's 'no we're not able to do this' and then they start interviewing other [hospice] agencies."

Other hospices relied increasingly on VA to offset costs. An oncologist shared that hospices seemed more receptive to veterans receiving concurrent care in recent years, and credited this to increased communication with VA around reimbursement.

> I don't think so much that the hospice agencies don't want [Veterans to have] chemo, as it is they don't want to be obligated for chemotherapy-related drugs which can be ultra-expensive. So, when we iron that out and say 'Okay, well you're coming to the VA to get this, you know, we wouldn't interfere with that.' So, I haven't run into barriers like that in …maybe the last 3 to 5 years. So, it's changed a lot.

At some sites, VA staff ensured veterans elected VA as payment source instead of Medicare to alleviate concerns from hospices about reimbursement and Medicare regulations. One palliative care nurse manager stated,

> Now the policy in what we've been doing all these years is giving them [Veterans] the option of Medicare versus VA. If they're getting any kind of treatment, I always do VA because I don't want the hospice agency having to deal with Medicare scrutiny and rules about what you know, we're doing since we're really doing something quite different than what Medicare allows.

In some locations, participants perceived concurrent care as inequitable because these therapies were not offered to their general Medicare population. One palliative care nurse manager shared,

> There were a couple of community [hospice]agencies that said, 'No. We cannot accept them [Veterans] when they're on those treatments because in the general population we can't do that.' And they felt that it was unfair for them to be able to care for this Veteran who was receiving chemo still while someone in the general population was not able to receive their services if they were still getting that palliative treatment.

When hospices prohibited concurrent care, some VA clinicians continued providing palliative care with referral to hospice after chemotherapy/radiation stopped, and other VA clinicians stopped referring to these hospices. Also, some VA clinicians felt there would be clarity if VA issued a formal policy on payment for concurrent care. One VA palliative care doctor summarized this, stating,

> From the VA I think what would truly help is having it very clearly spelled out that we are paying… This would really have to be a national sort of thing so that hospices don't feel like yes you'll [VA] pay for September and October and in November they're going to get stuck with a $2000 bill.

Discussion

This qualitative study is the first to provide an in-depth examination of processes influencing the use of hospice care along with cancer treatment including chemotherapy/radiation (i.e.,

[1] This reflects the Hospice Election language: "The individual's or representative's (as applicable) acknowledgment that the individual has been given a full understanding of hospice care, particularly the palliative rather than curative nature of treatment" [41].

concurrent care) for veterans with advanced cancer. Community hospice, VA palliative care, and VA oncology clinicians and staff perceived concurrent care as allowing veterans and their families to sustain hope and maintain relationships with VA clinicians, easing veterans' transitions to hospice. Liaisons coordinating care between VA and hospices were perceived as helping to promote concurrent care. However, participants shared many examples of difficulties in providing concurrent care across two different systems (VA and community hospices) and within the confines of the Medicare Hospice Benefit. Because there is no defined model to follow, provision of concurrent care varies and often depends on how hospices interpret financial and regulatory implications of caring for veterans who elect hospice while receiving cancer therapies, even when therapeutic intent is palliative.

Although a minority of veterans receive concurrent care [7], our research suggests that having this option available can have real benefit for veterans. This transitional approach has implications for symptom management, which is known to be significant among individuals with cancer [42]. In cases where chemotherapy/radiation is appropriate for symptom management, these treatments appear well-aligned with veteran-centric end-of-life care and, accordingly, VA places no restriction on receipt of concurrent care for veterans if care is coordinated and services are not duplicative. Many VA clinicians we interviewed stated they continued to provide care when their veteran patients enrolled in hospice. When concurrent care worked well, veterans arguably received high-quality, person-centered end-of-life care.

Themes identified may help understand why participants repeatedly raised concerns that receipt of chemotherapy/radiation was not in alignment with "hospice philosophy." Perhaps, hospice practitioners were concerned that without hard conversations about the "terrible choice," patients do not really understand they are dying and concurrent care is a delay tactic. However, our results would indicate that concurrent care is a transitional tactic allowing conversations to occur over time as patients understand how treatments affect them. Some hospice practitioners perceived complex care patterns introduced by concurrent care as inconsistent with traditional hospice philosophy and emphasized how critical liaisons are to coordinate care. One also cannot ignore the value of promoting the misalignment with hospice philosophy argument as a strategy to avoid perceived regulatory and financial risk associated with concurrent care. As stated in our results section, veterans and families must receive clear education that radiation or chemotherapy administered at this stage is for comfort care and symptom management.

The Centers for Medicare and Medicaid Services is currently testing a model of care that blends receipt of palliative care concurrent with active cancer treatment in efforts to improve quality of life and family/patient satisfaction for persons meeting hospice eligibility criteria [8, 9]. The Medicare Care Choices Model is designed to inform new payment systems, and while initially open to 30 hospices, 141 have now enrolled. While different from the terms of the Medicare model, our research suggests concurrent care can serve as a bridge to hospice in the final months of life, recognizing provision is limited by regulatory compliance concerns, complexity of care coordination, fiscal barriers, and knowledge gaps. As concurrent care models receive increasing attention in alternative payment models, addressing gaps is essential in refining end-of-life care delivery.

Limitations and future directions

Our focus on provision of concurrent care between VA and community hospices is a limitation and a strength. It is limiting as VA does not reflect the complex financial incentives under which concurrent care may be implemented outside VA. Nonetheless, our findings reveal how prominent these fears are and how they hinder concurrent care in non-VA settings. As what we observed in VA is largely positive, close observation will be needed to see whether similar outcomes are achievable under different and possibly distortionary Medicare incentives. Many clinicians from VA and hospices endorsed positive features and implications of concurrent care availability for veterans. Whether Medicare's concurrent care demonstration can achieve similar equipoise and positive outcomes is uncertain given different financial implications and absent extant, relevant measures.

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Compliance with ethical standards

We do not have a financial relationship with the funder, Department of Veterans Affairs Research and Development. This funding was in the form of a grant that was applied for and rewarded. We have full control of all primary data we collected ourselves and analyzed ourselves in this study, and we will allow the journal to review our data upon request.

Conflict of interest The authors declare that they have no conflict of interest.

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