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Including Family Caregivers In Seriously Ill Veterans' Care: A Mixed-Methods Study

ABSTRACT Family caregivers often serve as unpaid members of the home and community-based care workforce for people with serious illness; as key partners in the home-clinic continuum, they should be included in health care teams. The Campaign for Inclusive Care is an initiative within the Veterans Affairs health care system to improve provider practices for including caregivers of military members in treatment planning and decisions. We defined *inclusive care* using a literature review, provider interviews, and a caregiver survey. We found that inclusive care involves clear definition of the caregiver role, system policies for inclusion, assessment of caregivers' capacity, explicit involvement of caregivers, and mutuality in caregiver-provider communication. We recommend solutions based on this definition that can inform development of a national caregiver strategy, required of the Department of Health and Human Services by the Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2018.

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Family caregivers play a fundamental role in meeting the health and social care needs of people living with serious illness, and they function as intermediaries between home and clinic settings.[1–3] The National Alliance for Caregiving estimates that 34.2 million Americans have served as unpaid caregivers to an adult age fifty or older in the past twelve months.[4] The economic value of caregiving is substantial: It would amount to $522 billion per year if this free care were to be replaced with paid care.[5]

Without formal recognition, patients' caregivers will continue to be inconsistently identified by health care systems, engendering communication gaps between caregivers and providers and difficulty connecting patients with supportive services.[6–16] Over the past twenty years in the US, states and health systems have implemented policies to support caregivers.[17–19] The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2018, which requires the Department of Health and Human Services (HHS) to delineate a national strategy for recognizing and supporting family caregivers, has potential to effect widespread change.[20]

A new initiative to improve Veterans Affairs (VA) health care system providers' engagement with military caregivers, largely family or friends of veterans, called the Campaign for Inclusive Care, was launched in November 2017 by the Elizabeth Dole Foundation and Department of Veterans Affairs with funding support from the United Services Automobile Association (USAA) Insurance company. VA patients are an important serious illness population. They are sicker than the general US population, with higher prevalence of chronic diseases such as cancer and diabetes and, in turn, higher mortality risk.[21–23] Lessons from the Campaign for Inclusive Care can help health care systems increase caregivers' inclusion in the care of people with serious illness.

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Study Data And Methods

FRAMEWORK We used a critical literature review,[24] provider interviews, and a caregiver survey to specify components of inclusive care. To align this work with other health services research to improve health care quality, we attributed inclusive care components to structure and process aspects of the Donabedian model, which provides a framework for evaluating health care quality.[25] *Structure* describes features that shape context, including organizational policies or administrative guidance to standardize behavior. *Processes* are actions that affect care delivery—for example, the manner in which providers interact with families or patients. Solutions that modify the structure or process of health services to include caregivers could, in turn, facilitate the optimal use of home and community-based services to help people with serious illness maintain independence and remain longer in their communities.

LITERATURE REVIEW The critical literature review was conducted to develop the concept of inclusive care.[24] The review included papers published from January 1, 2005 (consistent with a prior RAND research inventory),[26] to January 30, 2018, that examined unpaid adult family caregivers' experiences with being included in or excluded from health care teams and explored mechanisms for including family caregivers. We constructed a database from a structured search of a primary health services database (PubMed) in collaboration with a university librarian experienced in systematic reviews. Six researchers (all authors of this article) reviewed papers at first the title and then the abstract level for eligibility, working in teams of two to arrive at consensus and resolve discrepancies within a full team meeting. We excluded papers that did not identify family members as caregivers, focused on caring for people under age eighteen, and did not present work conducted in Organization for Economic Cooperation and Development countries. We included empirical (qualitative or quantitative) and conceptual papers. Four researchers aggregated findings by developing codes to categorize content and generate conceptual categories essential to our evolving concept of inclusive care.

PROVIDER INTERVIEWS We elicited VA providers' perspectives via semistructured interviews with providers from the three Veterans Integrated Services Networks (VISNs) participating in the Campaign for Inclusive Care during 2018. We used a convenience sampling approach, with points of contact at each VISN providing a sampling frame that included a mix of roles (manager or service), disciplines (such as physician, nurse, or social worker), and settings (such as geriatrics or rehabilitation). Interview questions queried providers' experiences with and observations of caregiver inclusion in VA health care, focusing on how providers initiate communication and further interact with caregivers and how providers evaluate caregivers' capacity based on items from the Caregiver Perceptions about Communication with Clinical Team Members (CAPACITY) measure.[7] Providers were also asked about what improvements could be made in their facilities to better include caregivers. (See online appendix exhibit A for provider interview questions.)[27] Data were analyzed using the constant comparative approach[28] in which four qualitative researchers coded textual elements (such as "point person" or "big picture coordination"). The research team integrated these elements through discussion and consensus to form a list of topics relevant to inclusive care that included theoretical properties and dimensions (such as dedicating staff to work with patient-caregiver dyads).

CAREGIVER SURVEY We fielded a twenty-eight-item web-based survey to military caregivers from the Elizabeth Dole Foundation Fellows and Hidden Heroes community by posting a link on their secure Facebook groups. Screening questions asked respondents whether they assisted in the care and treatment of a wounded, ill, or injured veteran (for instance, assisting with bathing, dressing, or managing medical appointments) and whether they cared for a veteran who is enrolled in or eligible to access the VA health care system. Survey items included both open- and closed-ended responses. The caregiver survey covered the same domains as the provider interview guide, asking caregivers to respond to questions about interactions with providers, inclusion in health care encounters (using the CAPACITY measure),[7] and opportunities for improvement. (See appendix exhibit B for caregiver survey questions.)[27]

To integrate findings from our multiple methods, we matched topics identified in provider interviews, as well as results from the caregiver survey, with conceptual categories from the critical literature review. The literature review provided the overall framework, and the interview and survey data added context and nuance.

LIMITATIONS This study puts forth a definition of *inclusive care* that might not resonate in all settings. Although primary data were mostly derived from nurses and social workers in outpatient settings, it is important to consider that approaches may differ by practice setting and provider type or specialty. Furthermore, primary data collection, and thus practice recommendations, focused on military caregivers and the VA health care system; however, the literature re-

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Health care systems leadership should set caregiver inclusion as a systemwide priority.

view included other populations and settings. Future studies could enhance this definition of *inclusive care* by testing or adding components in different health care settings.

Study Results

CHARACTERISTICS OF SAMPLE Results derive from three distinct samples. We identified thirty-five papers from 2,788 records screened. The final provider sample included twenty-four providers from VA geriatrics ($n = 14$), rehabilitation ($n = 2$), and other patient care or clinical services ($n = 8$), with disciplines including social work ($n = 13$), nursing ($n = 9$), physical therapy ($n = 1$), and medicine ($n = 1$). The caregiver survey sample included ninety-four caregivers from thirty-nine states who completed all survey questions, with the majority being a spouse or partner ($n = 77$) and having provided caregiving from two to ten years ($n = 63$).

COMPONENTS OF INCLUSIVE CARE From the literature review, we identified five components of inclusive care: system-level policies for inclusion; clear definition of the caregiver role; explicit involvement of caregivers; assessment of caregivers' capacity; and mutuality in caregiver-provider communication. These components constitute structural and process aspects of care quality. Evidence from the provider interviews and caregiver survey, presented below, illuminate how these components of inclusive care manifest in practice and point to challenges and solutions for including caregivers in health care teams.

STRUCTURAL ASPECTS

▶ **SYSTEM-LEVEL POLICIES FOR INCLUSION:** Providers offered few examples of systemwide policies to include caregivers in health care teams. One noted practice is to administer the Zarit Burden Interview,[29] which assesses a caregiver's personal and role strain on a five-point scale prior to entry into the VA Caregiver Support Program. Providers who administer the Zarit Burden Interview said that, as standard practice, it offers value by providing an opportunity to talk directly with caregivers and, in turn, a view into caregivers' lived experiences. One nurse who provides care in a clinic primarily serving veterans with spinal cord injuries, amyotrophic lateral sclerosis, and multiple sclerosis said, "Our social worker just does it because he knows he has to, but the beauty in that is he usually takes the caregiver out of the room if they're available and speaks to them one-on-one. They can talk openly, they can ask questions that they may not feel comfortable asking in front of the veteran, and it really gives us a good idea of what's going on behind the scenes." Our caregiver survey identified several barriers to inclusion: 54 percent of respondents selected medical team member changes, 37 percent selected legal or privacy concerns, and 16 percent selected too much paperwork, which are all system-level barriers.

▶ **CLEAR DEFINITION OF CAREGIVER ROLE:** In their interviews, providers said that the caregiver role is too complex to define in a systematic way. Caregiver roles vary depending on context, such as disease or age. For example, caregivers of younger veterans may need to help to deescalate episodes of significant symptoms of posttraumatic stress disorder, whereas caregivers of older veterans may need to help with cognitive or memory limitations. Despite variability, providers said that a caregiver role typically involves extending the health care team in the home environment and representing their care recipients in the clinic environment, working to ensure continuity of care while advocating for their care recipients, who may have difficulty advocating for themselves.

Providers said that they often do not know the best way to navigate relationship dynamics to effectively identify or include a caregiver in the care process, particularly since caregiving can change the dynamic between partners. Patients become reliant on their caregivers; this reliance can negatively affect relationships, such as when a shifting power balance impairs intimate relationships. One social work manager from a hospital-based team that coordinates VA care for veterans transitioning from service said, "The necessity of flipping into caregiver role is really done out of loving concern but becomes like, I have an additional child, and that changes the dynamic." Providers indicated that one way to deal with complex relationships is to encourage veterans and their caregivers to take part in defining the caregiver role, including asking caregivers about their own goals, as there may be cognitive dissonance between a caregiver's expectations and a veteran's health needs.

Responses from our caregiver survey underscore uncertainty around recognizing family caregivers as having a role within health care teams. Approximately 40 percent of caregivers

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reported that providers are not aware of who the family caregiver is, which creates a barrier to caregiver inclusion. Additionally, according to 30 percent of caregivers, the larger care team does not know the caregiver. Responses to the question, "*In your own words, as a caregiver, what does it mean to be included as part of your veteran's health care team?,*" revealed various expectations and experiences: Caregivers indicated that as part of the health care team, they provide continuity of care (41 percent), serve as an advocate for their veteran (34 percent), and have access to professionals (32 percent).

PROCESS ASPECTS

▶ **EXPLICIT INVOLVEMENT OF CAREGIVER:** Providers said that they lack a consistent way to involve caregivers proactively in health care teams, especially in outpatient primary care and inpatient acute care settings. Providers described how primary care providers might not "think" to include family caregivers during hectic clinic schedules. They also said that discharge practices from acute care do not consistently include communication with caregivers. As a nurse manager in a geriatric postacute care facility said, "Sometimes I know that the nurses don't have time to do the education, especially when they are up on the acute care unit."

Providers offered several suggestions based on their experiences to place caregiver involvement front and center. One strategy included having a dedicated point person as part of the veteran's interdisciplinary health care team, with sole responsibility to act as a consistent contact for both the veteran and the caregiver. This person would focus on the "big picture" for well-integrated care. Other suggestions to facilitate access for caregivers included telephone and video communication, as well as delineating physical space that would be inviting to caregivers in clinical settings.

A majority (97 percent) of caregivers said that it is "important" to incorporate caregivers in their veteran's health care team. When asked if they feel welcomed as part of the health care team, 38 percent of caregivers replied affirmatively or neutral; in open-ended responses, 64 percent of caregivers reported that the extent of their inclusion depended on the provider or department. When caregivers were asked what challenges or barriers hindered their inclusion as part of the health care team, 52 percent chose time (for instance, medical staff are too rushed or do not have time to "deal with me or my concerns"). Caregivers recognized the benefits of being involved, including "Peace of mind for the person I care for and me" (78 percent of respondents), "I would understand my veteran's treatment plan" (66 percent), "I would understand my veteran's medication management" (56 percent), and "I would feel more in control of medical issues" (56 percent).

▶ **ASSESSMENT OF CAREGIVERS' CAPACITY:** Although delineating a standard role can help caregivers function within health care teams, knowledge about a caregiver's personal capacity is critical for tailoring their role. However, providers reported ambiguity about how and when to evaluate caregivers' capacity. For example, they noted that VA care is designed to focus on veterans, leaving providers limited time to assess veterans' caregivers. Providers said that while within the VA there are some available assessments of post-9/11 veteran caregivers' capacity, for the purposes of entry into the Program of Comprehensive Assistance for Family Caregivers, questions remain about the most effective way to assess caregivers' capacity. Providers said that the Zarit Burden Interview does not take into account caregivers' cognitive status, technical or physical capacity, or primary motivators.

Providers suggested that caregiver capacity assessment should take into account personal contextual factors. Providers said that their colleagues who work with caregivers ought to be "well-rounded"—that is, skilled in helping with a wide range of situations. Personal contextual factors may include identifying the level of motivation a caregiver has to perform necessary tasks, to protect the caregiver from negative outcomes such as caregiver strain and ensure the health and safety of the veteran.

Veterans' need and caregivers' capacity are dynamic entities, and providers said that it is important to continually support and develop caregivers' capacity to function in their roles. A physical therapist working in home-based primary care said, "It is hard when the veteran's condition has changed, ...and having the caregiver adjust to that is a challenge." Providers indicated that needs assessment (for example, caregivers' education needs) is as important as capacity assessment.

A majority (91 percent) of caregivers said that in the past six months their veteran's health care team "never" or "rarely" asked the caregiver if they needed help at home. Seventy-eight percent of the caregivers said that in the past six months the veteran's health care team "never" or "rarely" talked to them about community or in-home resources available to support their veteran. Meanwhile, 65 percent indicated that providers did not ask whether they had skills or training to help their veteran. Caregivers said that the main types of information discussed by the health care team were about medical aspects of care (managing medications, information about the patient's condition, and arranging medical ap-

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We offer guidance to shift toward a culture of inclusive care by clearly defining the meaning of inclusive care.

pointments), while the topics least discussed were service related (housing options, navigating health insurance, legal paperwork, and long-term services and supports).

▶ **MUTUALITY IN CAREGIVER-PROVIDER COMMUNICATION:** Providers indicated that to include caregivers, they must share the balance of power, which entails listening to what matters to caregivers and speaking to caregivers in plain language. In particular, providers noted the need to express empathy for caregivers' challenges while navigating complex systems of care—for example, with "active listening" during clinic visits and returning calls to help solve problems. Another nurse manager working in a geriatric postacute care setting said, "There's a special bond and understanding of what they've gone through and what their loved ones have gone through, especially if they were deployed, ...a lot of just listening to people, offering resources."

Caregivers expressed a need for a mutual style of communication. Fewer than half (38 percent) of caregivers surveyed said that health care teams understand "very well" or "well" the things that really matter to them about their veteran's health care. Sixteen percent said that within the past six months the veteran's health care team has "always" or "very often" asked for their ideas about managing their veteran's health. Thirteen percent said that their veteran's health care team was "always" responsive to their concerns about a treatment plan.

Recommended Strategies

Based on our findings, we suggest structure- and process-level solutions to guide development of inclusive care policies. (See appendix exhibit C for a summary of our recommendations.)[27] Although primary data for this study were collected within the context of the VA health care system, the core framework of inclusive care was derived from a literature review not limited to VA settings. We believe that our recommendations may inform the development of a national caregiving strategy as mandated by the RAISE Family Caregivers Act.

STRUCTURE Health care systems leadership should set caregiver inclusion as a systemwide priority. Providers indicated that VA regulations designed to protect veterans' personal information pose barriers; more than one-third of caregivers selected "legal or privacy concern" as a barrier to including caregivers in the sharing of information about veterans' care. Release of Information forms, required by the VA to share information with veterans' families or caregivers, do not take into account all contexts in which front-line staff operate. Streamlining legal and privacy regulations, which may require changes at the federal, state, or health system levels, in conjunction with templates in patients' electronic health records (EHRs) that capture caregiver information and notifications, would facilitate caregiver communication with health care teams.[3]

Health care systems should disseminate a standard definition of *caregiver*, with flexibility to tailor to individual needs and preferences. Providers reported lacking a systematic way to identify caregivers, and this was affirmed by caregivers' self-reports. An EHR template could prompt providers to identify family caregivers who might not self-identify—for example, as Joseph Gaugler and colleagues suggest, recognizing when one or more family members provide "support and help...[that] are not routine and are based on a care recipient's health need."[6(p493)] At the same time, health care teams should invite caregivers to contribute to patients' comprehensive shared care plans to further specify their role as a caregiver.[8–10] Comprehensive shared care plans, maintained in the EHR, are continually accessible to and updated by multidisciplinary members of a health care team, with rules to coordinate access determined by organizations and teams.[30] The plans should include caregivers' input as well.

PROCESS Health care professionals should proactively invite caregivers' participation, and veterans' preferences for this, in care team encounters and decisions along the continuum of care. Providers and caregivers reported that inclusion less often occurs in high-volume settings, such as primary or acute care. Providing caregivers with a question prompt list could guide efficient and informed conversations about patient care.[11] Additionally, a point of contact for patients and their caregivers, such as the Caregiver Support Coordinator, a facility-level Caregiver Support Program coordinator within

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the VA health care system, could help nurture the caregiver-patient dynamic. Finally, the Campaign for Inclusive Care is developing a series of webinars, the Academy for Inclusive Care, for VA providers to increase awareness about proactively including caregivers, imparting the importance of inclusive care and guidance for practice.

Health systems should develop processes for assessing caregivers' capacity continually over the course of a patient's care. Although VA providers use the Zarit Burden Interview to assess caregiver strain, a critical driver of caregivers' capacity to optimally care for patients, they report its inconsistent use. The Zarit Burden Interview should be more widely used in an effort to define caregivers' role strain in light of patients' needs and refer caregivers to appropriate resources. Additional assessment of the patient-caregiver dyad's social context may reveal issues constraining optimal health care. These data can help providers better understand veterans' needs, beyond the information they receive in brief clinical visits, to achieve successful health outcomes for patients and their caregivers.

Health care system leaders should develop processes that foster mutuality between caregivers and health care teams. Providers indicated that the relationship between the caregiver, who holds contextual information, and the health care team, which brings clinical knowledge, could be antagonistic. Caregivers and health care teams can reach an understanding of the valuable roles that each party plays in caring for patients. Process changes, such as actively listening to caregivers and empowering them to communicate their needs to providers, can lead to improvements in patient care. For example, the health care system in Ontario, Canada, has online training for providers that includes modules on understanding the role of, communicating with, and empowering caregivers.[31]

Conclusion

Caregivers largely function as an unrecognized, albeit critical, part of the workforce to meet home and community-based care needs for people with serious illness. The Campaign for Inclusive Care aims to change this dynamic, first within the VA health care system, by improving health care quality through more purposeful recognition of caregivers as valued members of health care teams. We offer guidance to shift toward a culture of inclusive care by clearly defining the meaning of inclusive care. Recommended strategies focus on standardizing practices through systemwide changes, role clarity, and regulatory advances, and changing care delivery through proactively involving caregivers, assessing capacity, and communicating mutually. Now that HHS has the RAISE Family Caregivers Act as a mandate for a national caregiver strategy, these suggestions are particularly timely. ■

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