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Family caregiver use and value of support services in the VA Program of Comprehensive Assistance for Family Caregivers

Nina Sperber, Courtney Van Houtven, Sara Andrews, Katherine Miller, Karen Steinhauser, G. Darryl Wieland, Valerie Smith, Jennifer Lindquist, Megan Shepherd-Banigan, Margaret Campbell-Kotler, Jennifer Henius and Margaret Kabat

Abstract

Context: The US Congress in 2010 established the Program of Comprehensive Assistance for Family Caregivers (PCAFC) in the Department of Veterans Affairs' (VA) healthcare system, expanding services for family caregivers of eligible veterans with injuries sustained or aggravated in the line of duty on or after 11 September 2001. The program includes a Caregiver Support Coordinator, stipends for caregivers, education/training, and additional services.

Objective: The primary goal of this study was to examine the types of services that family caregivers of veterans use and value, how services are used and any limitations family caregivers' experienced. Given that few interventions assess caregiver satisfaction with services, there is a gap in the existing literature addressing these outcomes.

Methods: We assessed how caregivers use and value services with a national, web-based survey (N=1,407 caregivers) and semi-structured phone interviews (N=50 caregivers).

Findings: Caregivers rated all services as helpful and especially valued financial support to be with the veteran, training in skills for symptom management, and assistance with navigating the healthcare system. A majority reported more confidence in caregiving, knowing about resources for caregiving and feeling better prepared to support the veteran's

progress and healthcare engagement. However, only a minority reported awareness of the full range of PCAFC services.

Limitations: There was a low response rate to the survey, which may have implications for generalisability to the whole population of caregivers accessing PCAFC. Additionally, we rely on self-report rather than objective measures of service use and outcomes.

Implications: This is the first in-depth examination of experiences of caregivers of using the innovative PCAFC model of support. It acknowledges the important role of caregivers in health and long-term (social) care delivery and can be used to inform development of strategies outside the VA healthcare system to recognise caregivers. Findings suggest that a system-wide program to effectively include caregivers as part of the care team should include mechanisms to help connect caregivers with an array of resources, options from which to find those which best fit their personal needs and preferences.

Keywords: Caregiver, veteran, long-term care services and supports.

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Background

Family caregivers who provide unpaid assistance to relatives or friends are central to the delivery of long-term care services and supports in the United States. Approximately 11–18 million Americans are family caregivers for an adult in need of long-term assistance (Kaye et al., 2010; Wolff et al., 2016). The number of care recipients in need of this type of care is expected to grow due to the ageing of the baby boom generation, increasing life spans, rising disability rates, the high cost of long-term care, and lack of financial resources (James & Hughes, 2016; Lakdawalla et al., 2004; National Academies of Sciences, Engineering and Medicine, 2016). Advances in medical care and technology enable care recipients to remain in their homes longer, outside long-term care facilities (James & Hughes, 2016; Lakdawalla et al., 2004). Although there is no definitive estimate of economic value afforded by family caregivers in the US, it is clear that there are societal benefits from family caregivers, including cost savings from delayed institutionalisation and paid home health services (Charles and Sevak 2005; Van Houtven & Norton, 2004; Van Houtven & Norton, 2008). Family caregivers need recognition for their integral role in the delivery of healthcare for adults, for example with healthcare delivery performance standards and quality measures that include caregiver engagement and outcomes. The National Academies of Sciences, Engineering, and Medicine (NAEM) Committee on Family Caregiving for Older Adults has advocated change in policy and practice, to better recognise the role that family members play in healthcare and address their personal education, economic, or psychosocial support needs, providing a person- and family-centered approach to care (National Academies of Sciences, Engineering and Medicine, 2016; Wolff et al., 2016).

The Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers (PCAFC), established by Congress in 2010 under Public Law (P.L.) 111-163, is a national program that provides education, coordination, health and financial support directly to family caregivers. The program is targeted to eligible veterans who sustained or aggravated a serious injury in the line of duty on or after 11 September 2001. Post-9/11 veterans (and thus PCAFC veterans) tend to be younger than veterans from other eras: 53% are aged 26–40 and 34% are aged 41–64. Among PCAFC veterans, 75% have post-traumatic stress disorder (PTSD) and 30% have a traumatic brain injury (TBI). Other mental illness is also highly prevalent (Van Houtven et al., 2017). As a result, caregivers of post-9/11 veterans are likely to report that their care recipients have a behavioural health or mental health/substance use condition and that they help their care recipients cope with stressful situations (Ramchand et al., 2014).

The number of applications for the PCAFC has far exceeded expectations, with over 37,000 applications received by 30 September 2014, almost eight times the initial

estimates (Miller et al., 2015). As of May 2016, the program has served over 32,000 caregivers and has cost over \$1 billion, with 80% of expenditure attributed to the monthly stipends to caregivers. The rapid roll out of the program, along with the higher than expected demand, has made it unclear whether services and supports offered at each medical center by the caregiver support coordinators (CSCs), the main local program points of contact, have had sufficient capacity to meet actual levels of needs.

The purpose of the present study was to evaluate how caregivers use and value PCAFC services. It was part of a larger program evaluation: a separate analysis evaluated short-term outcomes for veterans and caregivers who participated in the program, including financial strain, depressive symptoms, and healthcare utilisation (Van Houtven et al., 2017). Information about caregivers' perspectives on the value of the program and its specific components will augment the return on investment outlook with evidence of the real-life benefits of PCAFC to caregivers and information about the types of services that family caregivers of veterans use and value. Given that few interventions assess caregiver satisfaction with service, there is a gap in the existing literature addressing these outcomes (Shepherd-Banigan et al., 2017). Therefore, findings from this analysis could inform decisions about effective use of resources within the PCAFC and development of caregiver supports and services in the civilian population (Feinberg, 2012).

Methods

We used a mixed methods approach in which survey results detailed caregivers' quantitative ratings of the components of the PCAFC program and qualitative interview data provided context for and explanation of those findings. Survey and interview questions were designed to elicit caregiver perspectives on the main benefit(s) of being enrolled in PCAFC and awareness and the use of three core services (i.e. the monthly stipend paid to the caregiver, required caregiver skills training and support from the CSC) and eight additional support services (i.e. Building Better Caregivers™, the Caregiver Support Line, Caregiver Support Line Education Calls, the Peer Support Mentoring Program, self-care classes, respite care, mental health services, and travel expenses to attend the required training and the veteran's medical appointments). Qualitative and quantitative data were collected and analysed independently and integrated at the analysis phase; interviewers were blinded to survey results while conducting interviews. This study was assessed by the Durham VA Healthcare System Institutional Review Board (IRB) and determined to be an operations study and thus exempt from IRB review.

Quantitative data were collected via a web survey. An approximately ten-percent stratified sample by VA Medical Center of caregivers enrolled in PCAFC for at least 90 consecutive days were invited to participate in the survey

(N=10,000). The final analytic sample was n=1,407 (response rate of 14%). Data were analysed using descriptive statistics. Qualitative data were collected via 30–45 minute semi-structured phone interviews with 50 caregivers enrolled in PCAFC. Using telephone numbers provided by the PCAFC tracking database, five caregivers were recruited from lists provided by CSCs from each of ten VA Medical Centers (VAMC), purposefully selected to represent VAMC-level variation in PCAFC application approval rates, geographic region, and facility complexity level (a ranking from VA administrative data that includes size of patient population, breadth of clinical services, and affiliation with an academic institution) (see table 1). We did not specifically recruit from survey respondents for the interviews and do not know if any of the interviewees also completed the web survey. Interviews were audio-recorded and transcribed. Data were analysed by coding to discern patterns and themes.

Table 1. Characteristics of VA Medical Centers from which caregivers were recruited for an evaluation of the VA Caregiver Support Program

| Characteristic | VAMC ^a N (total = 10) |
|--|-------------------------------------|
| PCAFC application approval rate at VAMC | |
| High (76–100%) | 3 |
| Medium (51–75%) | 4 |
| Low (≤50%) | 3 |
| US geographic region of VAMC | |
| Northwest | 3 |
| Southwest | 1 |
| Southeast | 2 |
| Northeast | 2 |
| Mid-west | 2 |
| Facility complexity level of VAMC ^b | |
| 1 | 6 |
| 2 | 3 |
| 3 | 1 |

Notes

a. VAMC=Veterans Affairs Medical Center.

b. Facility complexity level is a ranking from VA administrative data that includes size of patient population, breadth of clinical services, and affiliation with an academic institution: 1=most complex, 3=least complex.

Results

Participant characteristics

Table 2 displays characteristics of PCAFC caregivers included in the quantitative and qualitative analyses. Although the interview group was recruited separately from the survey sample, they mirrored the overall survey respondents in a

number of characteristics. The average age was similar, 43 for survey respondents and 42 for interview respondents. For both samples, the majority were female, White, and a spouse of the care recipient. A few caregivers in each sample were veterans themselves.

Use and value of core program services

Stipend

PCAFC caregivers receive a monthly, tax-free stipend awarded according to a three-tiered system based on the veteran's level of care needs. The rate of pay is based on the Bureau of Labor Statistics adjusted hourly salary of a home health aide in the veteran's geographic area. This stipend is paid directly to the caregivers as an 'acknowledgment of the sacrifice that they make to care for seriously injured veterans' (Feinberg, 2012) and is not meant to replace income or denote an employment relationship with the Department of Veterans Affairs.

Most caregivers surveyed (40%) received the middle tier level (tier 2) stipend, although the sample was relatively evenly distributed across the three tiers (table 2). When asked to rate helpfulness of PCAFC services on a scale of 1 ('least helpful') to 10 ('most helpful'), the mean caregiver rating for the stipend was 8.8 (figure 1). PCAFC caregivers in qualitative interviews described the stipend as having a positive impact on their ability to care for their relatives/veterans by giving them more flexibility and choice. For example, because of the stipend, caregivers could spend time with their relative, defray costs of activities enjoyed by the veteran, or invest more in their own self-care, thus helping them cope as a caregiver for longer. Caregivers said that this flexibility is particularly important for caring for someone with a mental health disability/psychiatric disability like PTSD. One caregiver described how this flexibility has helped her and her relative:

For us personally, it's been a life saver ... it's allowed me to be able to stay home and take care of him and make sure that everything runs smoothly. That way when we do have an anxiety issue we can kind of move through it because we've already planned for everything else so there's nothing else to worry about.

Caregiver Support Coordinator

To enhance local access to program services, a Caregiver Support Coordinator (CSC) position was established at every VA medical center. As the program has grown, additional positions were added, with some medical centers having multiple CSC positions. The CSCs are experienced social workers, psychologists and nurses. They serve as the clinical experts on caregiving issues and are the primary points of contact for caregivers and medical center personnel. CSCs assist with the PCAFC application process, provide personalised information, refer caregivers to needed VA and

Table 2. Characteristics of caregiver survey and interview participants for the evaluation of the VA Caregiver Support Program

| | Survey respondents (N=1407) % (n) | Interview respondents (N=50) % (n) |
|---|--------------------------------------|---------------------------------------|
| Age, mean years (SD; n) | 43 (12; 1,260) | 42 (10; 49) |
| <i>Gender</i> | | |
| Missing | 0.3 (4) | - |
| Female | 94 (1,323) | 90 (45) |
| Male | 6 (80) | 10 (5) |
| <i>Race</i> | | |
| Missing | 7 (100) | 12 (6) |
| White | 59 (828) | 64 (32) |
| Other | 34 (479) | 24 (12) |
| Hispanic | 24 (337) | 12 (6) |
| <i>Relationship to veteran</i> | | |
| Missing | 0.4 (5) | - |
| Spouse | 85 (1,191) | 80 (40) |
| Parent | 10 (146) | 20 (10) |
| Other | 5 (65) | - |
| <i>Caregiver education level</i> | | |
| Missing | 2 (32) | - |
| High school/GED or less | 20 (287) | 14 (7) |
| Trade/technical/vocational school/some college credit | 35 (490) | 4 (2) |
| College/associates' degree/higher | 43 (598) | 82 (41) |
| Caregiver is also a veteran | 9 (131) | 18 (9) |
| <i>Caregiver insurance status^a</i> | | |
| Missing | 3 (47) | - |
| Tricare insurance | 39 (552) | - |
| Private insurance | 24 (333) | - |
| Champ VA (from CSP ^b) | 17 (234) | - |
| Champ VA (not from CSP ^b) | 7 (104) | - |
| Medicaid | 5 (73) | - |
| Other | 24 (336) | - |
| <i>Stipend tier level^c</i> | | |
| Stipend tier 1 | 27 (384) | 18 (9) |
| Stipend tier 2 | 40 (565) | 14 (7) |
| Stipend tier 3 | 33 (458) | 22 (11) |
| Stipend tier unsure | 0 (0) | 46 (23) |

Source: Authors' analysis of data from surveying and interviewing caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.

Notes

a Categories are not mutually exclusive. Multiple responses were allowed.

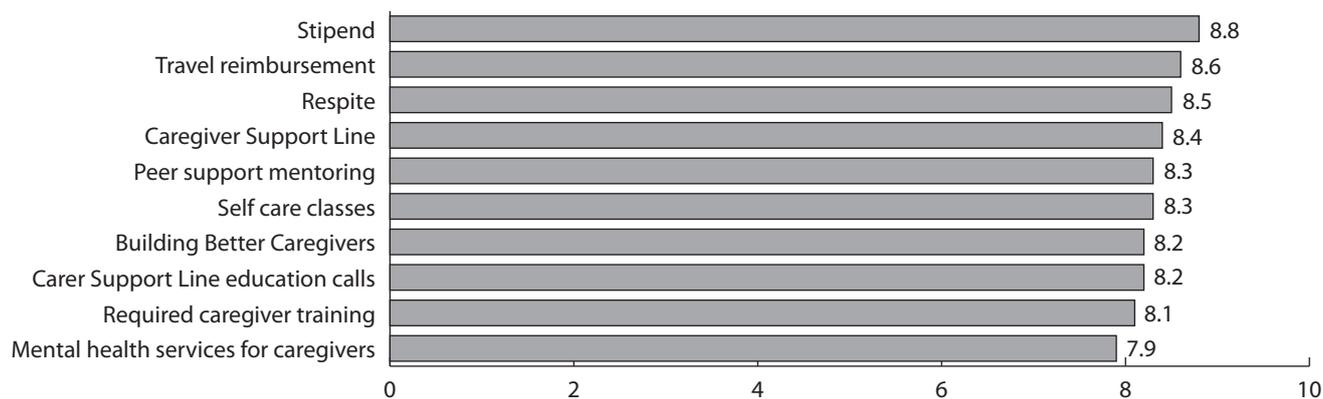
b Caregiver Support Program

c Stipend tier level as of July 2015 was determined through the Caregiver Application Tracker (CAT) among survey respondents. Stipend tier level was self-reported for interview respondents.

community services and supports, conduct quarterly monitoring assessment visits and lead caregiver education and support groups. All caregivers have contact with the CSC as part of the initial eligibility assessment process and meet to discuss services available to them once their application is approved.

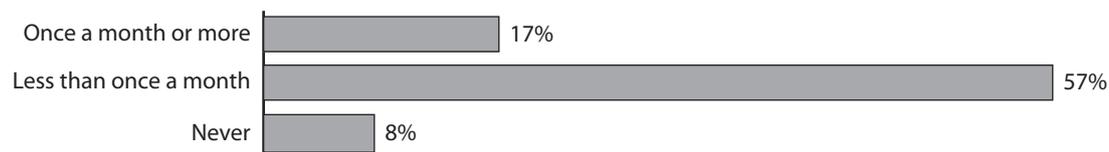
About three-quarters (74%) of the respondents to the survey had talked to their CSC since joining the program. However, the frequency of contact was relatively low, with

most (57%) saying that they talked less than once a month (figure 2). In general, PCAFC caregivers reported being connected to their CSC beyond the initial eligibility assessment. PCAFC caregivers who were interviewed reported contacting their CSC primarily for referrals to other caregiving services and support for obtaining their veterans' health-care (figure 3). Caregivers said that they valued 'knowing that someone cares', as one caregiver expressed it, within the large, complex VA healthcare system. They regarded the

Figure 1. Reported helpfulness of caregiver support services by caregivers in the VA Program of Comprehensive Assistance for Family Caregivers

Source: Authors' analysis of data from surveying caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.

Note: Caregivers were asked to rate helpfulness of services that they were aware of and had used.

Figure 2. Reported contact with Caregiver Support Coordinators by caregivers in the VA Program of Comprehensive Assistance for Family Caregivers

Source: Authors' analysis of data from surveying caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.

Note: Caregivers were asked to report how frequently they had contact with the Caregiver Support Coordinators.

Figure 3. Reported use of Caregiver Support Coordinators by caregivers in the VA Program of Comprehensive Assistance for Family Caregivers

Source: Authors' analysis of data from surveying caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.

Note: Categories are not mutually exclusive. Caregivers were asked, 'Since you joined, have you used your CSC for any of these reasons?'

personalised contact and follow-up they received from CSCs related to their relative's care as a major benefit of being in PCAFC, as compared with 'feeling like a number' when they interacted with other parts of VA.

Required caregiver training

As part of the eligibility determination process, caregivers who apply for PCAFC are required to complete a training curriculum that covers ten core competencies (e.g. caregiver self-care, medication management, home safety) which are meant to provide the caregiver with the knowledge and skill to assist their relative with personal care functions in everyday living. The training is available in English and Spanish, and caregivers have the option to complete it at home, via an online or workbook/DVD course, or in a classroom. As of

October 2012, the vast majority of caregivers had received training online or by workbook, rather than in a classroom.

PCAFC survey respondents indicated that the required caregiver training was helpful to them, rating it 8.1 on a 10-point scale (figure 1). Interview respondents reported that required training was helpful because they could apply what they learned in their daily caregiver roles. The training also provided activities to assist the caregiver to plan for potential emergencies, such as providing support if the veteran is suicidal. Caregivers found it helpful to have access to the course material to use as a reference after completing the training. As one said, 'What I like to do is go back through the book, and then get refreshed on it. I learn a little bit more. And then I try to apply that, what I've learned.' Those who had been functioning as a caregiver prior to joining

PCAFC said that by participating in the training they felt better equipped to manage their role. As one said:

You know, they teach me that I have to calm him down. That I have to ... make sure he has all his medication on time. You know, a lot of things that I didn't know, and they teach me – they show that if it is something that is out of my control, I have to call for her [CSC].

Use and value of additional program services

The PCAFC expands VA services that were in place prior to the legislation. We asked caregivers in the survey to indicate if they were aware of or had used any of these services and to rate their level of helpfulness. Although all eight services were generally rated as highly helpful (figure 1), there was relatively low reported use of these services (figure 4). Respite and mental healthcare were prominently discussed by caregivers in qualitative interviews as services that they valued but less frequently accessed, and thus we describe their experiences with these additional services below.

Respite care

Caregivers of veterans, regardless of whether they are in the PCAFC, can arrange for up to 30 days of respite care per year in a variety of settings, including at home, in a VA Community Living Center or a community-based program. The service is intended to give the caregiver a break, and can be offered to caregivers who are experiencing burden with which they are struggling to cope. It can be used as a few hours of care a day or week so that the family caregiver

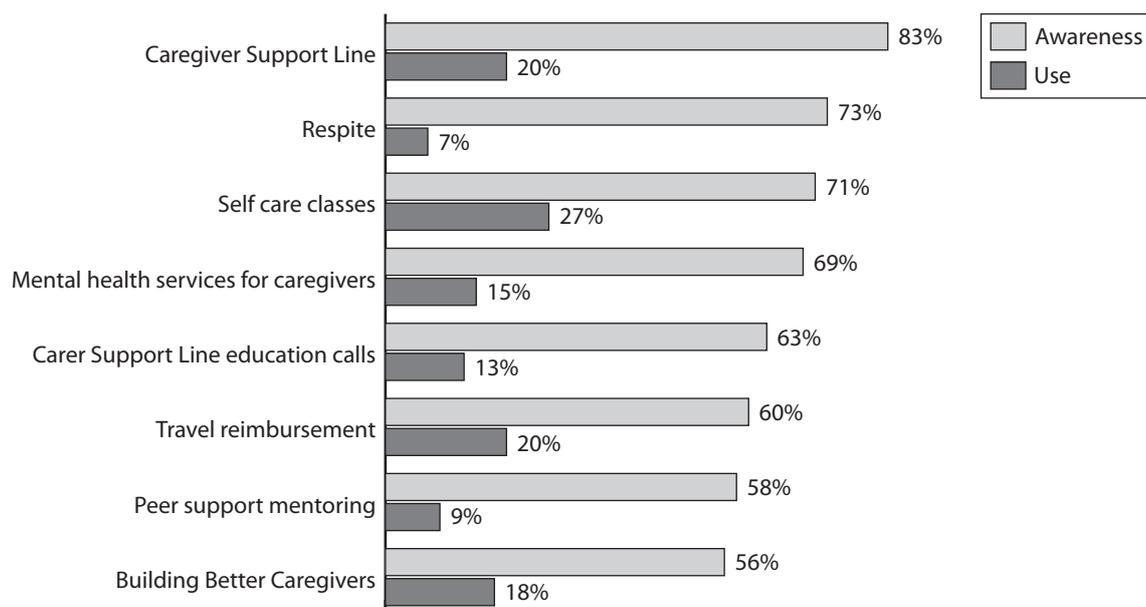
can, for example, run errands. It can also be used for several consecutive days, for example if a caregiver needs to go out of town. Under P.L. 111-163 and associated regulations, the respite benefit is enhanced for caregivers in PCAFC beyond the 30-day limitation. The PCAFC also offers respite care to caregivers while they are in the application process, so that the veteran may obtain care while the caregiver completes training requirements.

Respite care was highly valued by PCAFC caregivers (helpfulness rated 8.1 on a 10 point scale, figure 3), though there were significant barriers to use, as indicated by survey responses. Although 73% of respondents reported being aware of respite care, only 7% reported having used the service. One reason for low use cited by caregivers was that veterans with TBI/PTSD struggled to engage with strangers. Thus, receiving care from an unfamiliar individual would potentially create a more stressful situation. Additionally, some felt they had other sources of support, such as family members, which they would rather use should they need a break. Finally, caregivers who had childcare responsibilities said that respite care might allow them to have time off from caring for their relative but not their children and, therefore, did not provide a true break.

Mental health services

VA caregivers, regardless of whether they are in the PCAFC, can receive supportive counselling around issues related to the veteran's treatment. Under P.L. 111-163 caregivers participating in PCAFC can receive mental health counselling to address their own individual concerns. P.L. 111-163

Figure 4. Reported awareness and use of caregiver support services by caregivers in the VA Program of Comprehensive Assistance for Family Caregivers



Source: Authors' analysis of data from surveying caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.

Note: Respondents were asked to mark all services of which they were aware and had used. Missing and 'unaware of service' categories are combined, and the missing and 'did not use' categories are combined. The percentages of use should be interpreted as percent of all caregivers who were aware of service.

allows the VA to provide mental health services directly to caregivers or contract for this care as needed to meet their needs. Mental health services available to qualified caregivers include individual counselling, group therapy, and peer support groups. Although the PCAFC provides expanded access to counselling and support services, it does not include medication, inpatient psychiatric care, or medical procedures related to mental health treatments for caregivers.

PCAFC caregivers rated the helpfulness of PCAFC mental health services as 7.9 out of 10. As with respite care, a majority (69%) of survey respondents said that they were aware of this service, although a minority (15%) said that they had ever used it. Interview respondents said that they had not used the service because it was not recommended to them or that they believed they did not need personal therapy. Interview respondents who had used mental health services said that the service was important to them for stress reduction and self-care as well as for building confidence in their ability to handle difficult situations. Through this service, they were able to focus on their own needs and concerns as well as learn how to better help their relative. One caregiver said:

It really helped me to be better able to help my husband and help him work. He wasn't really participating in his therapy, and just the things that I learned and how I was able to get a better handle on the situation kind of helped him to participate more. So he is better now than he was.

However, many caregivers said that they wanted more opportunities to participate in a group format to connect with

others and know that they are not alone in their struggles.

Value of program

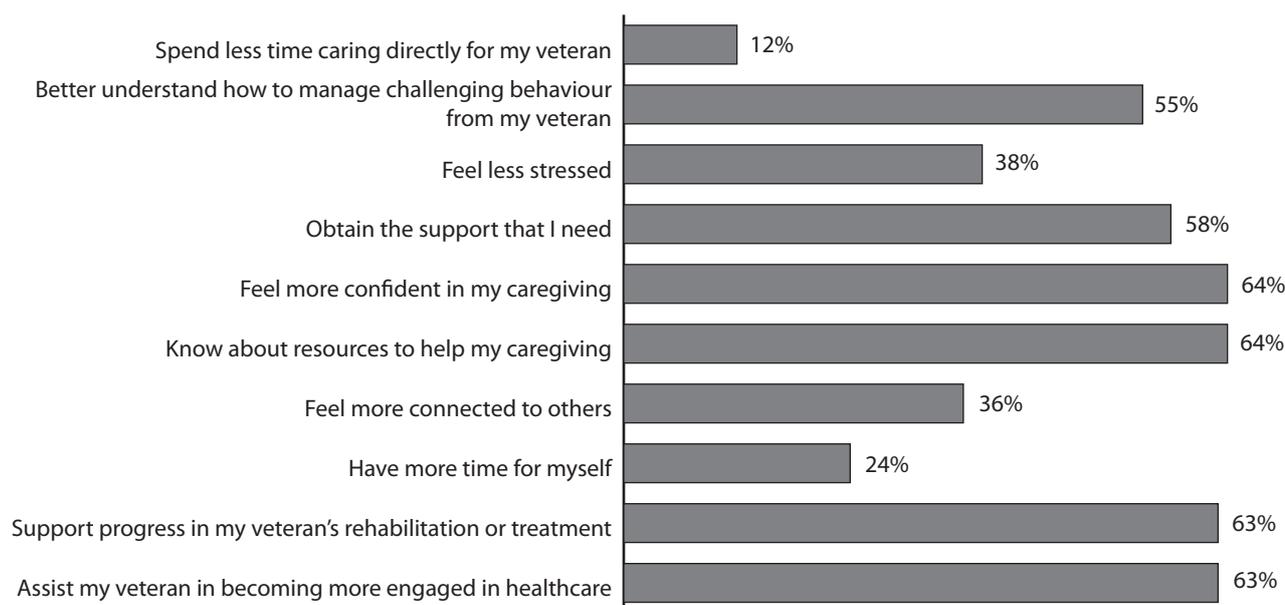
The purpose of the PCAFC is to support family caregivers of veterans, many of whom are on a path to recovery. Recovery may have a different meaning for each veteran-caregiver dyad; it can be based on the dyad's own goals and may include their own inherent assessment of the veteran's ability to regain full independence. Recovery could mean the veteran returns to work, or that experiences of hypervigilance (a symptom of PTSD marked by a state of excessive and exaggerated alertness and sensitivity to sensory stimuli) are reduced, e.g. from ten times to once per day (American Psychiatric Association, 2013).

Participation in PCAFC seeks to enhance the veteran's own engagement in treatment and recovery through a program of support services for his or her primary care partner. The value of this support was assessed via a survey question that asked caregivers to indicate the extent to which they agreed, on a 5-point scale, that the program has helped them with 10 items relating to their experience with being a caregiver of a veteran. Questions were developed to reflect intended outcomes of participation in the PCAFC (figure 5).

A majority (63–64%) of PCAFC caregivers surveyed strongly agreed/agreed that by participating in PCAFC they felt more confident in their caregiving, knew about resources to help with caregiving responsibilities and felt better prepared to support the veteran's progress and health-care engagement.

PCAFC caregivers said that the PCAFC helped them to

Figure 5. Reported value of the Caregiver Support Program by caregivers in the VA Program of Comprehensive Assistance for Family Caregivers



Source: Authors' analysis of data from surveying caregivers enrolled in the Program of Comprehensive Assistance for Family Caregivers, 2015.
 Note: Caregivers were asked to rate how much the Caregiver Support Program had helped with each of the items above on a 5 point Likert scale where 1 is strongly disagree and 5 is strongly agree. Responses were dichotomised into strongly agree and agree versus neutral, disagree and strongly disagree. Missingness ranged from 15–17% with 16% missing on average per item.

develop confidence in their ability to live with and care for veterans with mental health needs. Additionally, by participating in training, some caregivers said they learned specific skills to assist in caring for their relative and managing care and as a result felt less overwhelmed. For example, one caregiver said that training gave her confidence to set boundaries and to realise that it is 'okay to go to the store' or do things for herself and that she could leave her partner at home without feeling guilty. Another said she gained confidence in her judgment to know that she is on the right track. PCAFC caregivers also reported that they learned techniques for organising paperwork, medications, and appointments. One caregiver said that receiving a book in the mail with information about caregiving services gave her 'tools ... for building confidence' when asking for services or help for the veteran or herself. Having a formalised caregiver relationship with their relatives that was validated by providers helped to bolster caregiver confidence as well. As one caregiver said, 'Basically, [providers] trust me to do these things.'

Caregivers said that the PCAFC had provided them with links to resources that they need to care for veterans at home. Caregivers described their role as being like a navigator for the veteran, to help the veteran access and use services provided by the VA. As one said:

You can be a caregiver, but you want to be an effective caregiver ... To help that individual ... and be able to meet the needs of that individual ... you need to know about the resources, and what's available ... I would like to learn a little bit more about the structure of VA, so we are able to refer ... my son, whoever it may be, to the places where they'd be able to go and get what they need.

Regardless of whether or not the process for obtaining resources was smooth, it was still valuable for caregivers to not feel that they were managing on their own, to feel that they have 'a lifeline.' As one explained, 'Like I said, a lot of times, I couldn't get things from his doctor before the ... [PCAFC]. I was constantly calling his nurse case manager.'

The PCAFC has helped caregivers to support progress in veterans' rehabilitation or treatment directly. By providing them with specific strategies, it enables caregivers to intervene to help their relative, participate jointly in the veteran's health appointments, and help the veteran to access appointments. Caregivers described 'being there' for their relative by participating in the veteran's medical appointments. As one caregiver said, 'It's allowed me to stay with him and get things that we need to get done, like doctors' appointments...[and] make sure he's taking all of his medications, and getting some kind of exercise.' However, there were cases in which caregivers said that their input was dismissed by providers, for example when the caregiver felt the need to correct or add information provided by the veteran about his situation.

Caregivers indirectly supported the veteran's progress in rehabilitation or treatment by being available to drive them

to appointments. For example, one caregiver said, 'If I didn't have the [PCAFC], I would still work 40 plus hours a week, which would mean the ability for my husband to go to any of his appointments would be pretty much non-existent.' Another caregiver stated, 'I was trying to get Veteran's Choice [a program that authorises veterans to receive health care in their communities rather than waiting for or travelling to a VA facility] for him, and they're like, 'Well he can physically get in the car.' I'm like, 'Yeah, but mentally he can't. It's torturous for him. He does not want to get in the car with our four year old screaming for an hour and a half.'

Discussion

This evaluation of the VA PCAFC found that caregivers, who generally are younger and caring for veterans with stress and behavioural conditions, rate PCAFC program components highly and particularly value services that help them 'to be there' for the veteran and navigate the VA health system. However, they reported limited use of some services. These results have policy implications that align with recommendations from the NASEM Committee on Family Caregiving for Older Adults, suggesting that a National Caregiver Strategy could potentially have far-reaching impact, beyond caregivers of older adults (National Academies of Sciences, Engineering and Medicine, 2016).

Caregivers rated program components highly, with the stipend rated highest, though not much higher than other PCAFC services. The NASEM committee recommends development of evidence-based federal policies to provide economic support for working family caregivers to help offset economic costs from having to withdraw partially or completely from the labour force; findings from the present evaluation shed light on the potential impact of directly paying caregivers. The PCAFC stipend is intended to recognise caregiver efforts rather than provide economic support; however, caregivers indicated that the stipend additionally gave them some degree of economic freedom, empowering them to better care for their relative in a way that suited them and their families. This element of choice is akin to consumer-directed, person-centered care, in which individuals who need long-term care receive a budget to choose their own mix of services instead of having service providers decide for them. Research has demonstrated that consumer direction can have better outcomes than direct provision of services (Doty, 2004). The Cash and Counselling Demonstration and Evaluation (CCDE) is one such program, in which Medicaid consumers in three states were provided a cash allowance with which they could choose services, including hiring a family caregiver. CCDE has demonstrated good outcomes for care recipients and their caregivers (Brown et al., 2007). One unique aspect of the PCAFC is that it is a person- and family-centred program that is geared toward a personalised sense of recovery. Thus the stipend payment could potentially function as a disincentive to recovery for

the veteran, as discharge from PCAFC would result in the loss of supportive services that are specific to the PCAFC (e.g. the stipend, additional respite care, additional mental health counselling). The same is true in traditional Social Security Disability Insurance (SSDI), in which some people do not re-engage fully in paid employment in order to preserve their status as 'disabled' to receive continued payments (Maestas et al., 2013). We were not able to investigate this potential perverse incentive in this study but it may be worth investigation in further research.

Our results indicate that PCAFC caregivers value the CSCs as navigators to help them access resources for themselves and the veteran within a large and complex healthcare system. Researchers found in a study using administrative data that veterans with caregivers in PCAFC had greater outpatient care one to three months after enrollment than veterans whose caregivers had applied but not been accepted into PCAFC (Van Houtven et al., 2017). These findings suggest that, at least in the short term, caregivers in PCAFC do in fact help their veterans to better access outpatient healthcare resources within VA. CSCs are also tasked with evaluating caregivers prior to their entry into the program for their potential to support the veteran's recovery. Similarly, the NASEM committee recommends that a nationally coordinated transformation to person- and family-centered care should begin with adoption of 'mechanisms to systematically identify and support family caregivers throughout care delivery...' (Wolff et al., 2016).

This evaluation also offers potential transferrable evidence about the impact of the array of caregiver support services needed to transform the wider US healthcare delivery infrastructure into one that is person- and family-centered. Although there is clear evidence that programs which directly support caregivers yield increased caregiver confidence or delay the care recipient's institutionalisation, most interventions which have been evaluated have been tested in randomised clinical trials, and may not be capable of direct operationalisation in everyday practice settings (National Academies of Sciences, Engineering and Medicine, 2016). Our findings show that caregivers value the standard skills training that is a required component of enrolment into PCAFC. Additionally, there is a menu of support services offered through the PCAFC, and, while caregivers appreciate having options, our evaluation revealed that these services did not necessarily meet their specific needs and/or were not readily accessible. Particularly, respite care was highly valued as a way for caregivers to attend to their own needs but was used infrequently due to a lack of options that matched the requisites of this population, specifically veterans with behavioural health and stress coping needs or younger caregivers with smaller, dependent children at home.

Limitations

By integrating qualitative and quantitative methods, we were able to evaluate how caregivers use and value the services of PCAFC. We used a stratified-random sample to survey caregivers about what services they use and how helpful they found them. However, we were limited in the extent to which we can infer that survey responses reflect the national PCAFC program population. Additionally, we are relying on self-report rather than objective measures of service use. Our sample was mostly White and female, and future research could recruit a more diverse group of caregivers to explore subgroup experiences. Future studies could incorporate objective measures of service use and triangulate the caregiver perspective with views and experiences of other stakeholders, such as veterans and service providers. A strength of this study is that we developed semi-structured interview questions that aligned with structured survey questions to obtain a multi-dimensional picture of how useful the PCAFC program has been for caregivers.

Conclusions

The PCAFC is a unique program within the US to support caregivers, an important goal of a person and family-centered approach to healthcare. A system-wide program to effectively include caregivers as part of the care team should include dedicated coordinators to help connect caregivers with an array of resources; some services would need to be relevant to specific needs of population subgroups, such as (in this study) younger caregivers for individuals with behavioural and stress coping conditions. This snapshot of caregivers' experiences with, and valuation of, PCAFC services will be useful to inform future endeavours such as the development of a National Caregiver Strategy that seeks structural change to recognise caregivers as integral members of the healthcare team.

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