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AWARD NUMBER: W81XH-17-C-0022

TITLE: Interventions for Parent Caregivers of Injured Military/Veteran Personnel

PRINCIPAL INVESTIGATOR: Linda O. Nichols, PhD

CONTRACTING ORGANIZATION: Research, Inc at Memphis VA Medical Center/

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14. ABSTRACT This randomized clinical trial of 160 parent caregivers of combat wounded adult children, half in each arm, will compare 6 30-minute online webinars to 6 one-hour individual sessions modeled on the REACH VA caregiver intervention, focusing on education, skills building and support over three months. Hypotheses were Education Webinar arm participants will improve on outcomes, including depression, anxiety, and burden and REACH (Resources for Enhancing All Caregivers' Health) individual sessions, compared to Education Webinars, will be more effective in improving outcomes. Study aims were to Determine effective strategies for providing education, skills building and support for stressed and burdened parent caregivers of injured returning service members; Determine feasibility of conducting interventions with parent caregivers; Determine characteristics of those recruited; Determine satisfaction; Determine commitment and adherence to therapeutic recommendations; and Develop manuals for clinical translation. Data were collected at baseline, 3, and 6 months.					
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TABLE OF CONTENTS

	<u>Page No.</u>
1. Introduction.....	4
2. Keywords.....	4
3. Accomplishments.....	4
4. Impact.....	6
5. Changes/Problems.....	7
6. Products.....	9
7. Participants & Other Collaborating Organizations.....	12
8. Special Reporting Requirements.....	14
a. Quad Chart.....	16
b. Recruitment and Retention.....	17
c. Consort Diagram.....	18
9. Appendices	
Appendix 1. W81XH-17-C-0022 - Interventions for Parent Caregivers of Injured Military/Veteran Personnel Findings – Hypotheses and Aims	
Appendix 2. Final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (in progress)	
Appendix 3. Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, submitted to <i>The Gerontologist</i> , June 2020	
Appendix 4. Dissemination Activities	

1. **INTRODUCTION:** Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.

This randomized clinical trial of 163 parent caregivers of combat wounded adult children, half in each arm, compared six 30-minute online webinars to six one-hour individual sessions modeled on REACH VA caregiver intervention, focusing on education, skills building and support over three months. Hypotheses are that Webinar arm caregivers would improve and caregivers in REACH arm would improve more in depression, burden, and anxiety. Data collected at baseline, 3, and 6 months.

2. **KEYWORDS:** Provide a brief list of keywords (limit to 20 words).

Parents, Adult Children, Caregivers, Military Personnel, Veterans, Multiple Trauma, Stress Disorders, Post-Traumatic

3. **ACCOMPLISHMENTS:** The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer whenever there are significant changes in the project or its direction.

What were the major goals of the project?

List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project, identify these dates and show actual completion dates or the percentage of completion.

1. Prepare regulatory documents – target SEPT 17 – completed SEPT 17
2. Obtain study staff – target JUL 17 – completed OCT 17
3. Finalize protocol – target SEPT 17 – completed AUG 17
4. Recruit participants – target JUN 19 – completed MAY 19
5. Screen participants – target JUN 19 – completed MAY 19
6. Randomize – target JUN 19 – completed JUN 19
7. Deliver intervention – target SEPT 19 – completed SEPT 19
8. Collect and enter data – target FEB 20 – completed MAR 20
9. Analyze data – target MAR 20
10. Prepare and disseminate results – target JUN 20 – in process

What was accomplished under these goals?

For this reporting period describe: 1) major activities; 2) specific objectives; 3) significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative); and/or 4) other achievements. Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.

Caregiver burden was related to veteran TBI diagnosis, aggressive behavior toward others, and functional limitations. Both interventions provided significant benefit for parent caregivers in depression, anxiety, and burden during the course of the study. Please see attached documents:

- W81XH-17-C-0022 - Interventions for Parent Caregivers of Injured Military/Veteran Personnel Findings – Hypotheses and Aims (Appendix 1)
- Final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 2)
- Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 3)

What opportunities for training and professional development has the project provided?

If the project was not intended to provide training and professional development opportunities or there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe opportunities for training and professional development provided to anyone who worked on the project or anyone who was involved in the activities supported by the project. “Training” activities are those in which individuals with advanced professional skills and experience assist others in attaining greater proficiency. Training activities may include, for example, courses or one-on-one work with a mentor. “Professional development” activities result in increased knowledge or skill in one’s area of expertise and may include workshops, conferences, seminars, study groups, and individual study. Include participation in conferences, workshops, and seminars not listed under major activities.

Nothing to report

How were the results disseminated to communities of interest?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

Please see Dissemination Activities (Appendix 4)

4. IMPACT: Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:

What was the impact on the development of the principal discipline(s) of the project?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how findings, results, techniques that were developed or extended, or other products from the project made an impact or are likely to make an impact on the base of knowledge, theory, and research in the principal disciplinary field(s) of the project. Summarize using language that an intelligent lay audience can understand (Scientific American style).

REACH VA programs are delivered to caregivers of Veterans and Veterans who are caregivers across the VA health care system as individual sessions or telephone support groups. Caregivers can be served from the VA’s national Caregiver Center located at the Memphis VA Medical Center or by a trained Program Coach at each VA facility. Staff will be able to offer the REACH VA Parent program, using the Parent Caregiver Notebook and Risk Assessment. The Parent materials will be made available to each VA facility and will be used by them and the Caregiver Center to serve parent caregivers.

What was the impact on other disciplines?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how the findings, results, or techniques that were developed or improved, or other products from the project made an impact or are likely to make an impact on other disciplines.

See above. Staff who offer REACH VA are from multiple disciplines including social work, psychology, and counseling.

What was the impact on technology transfer?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe ways in which the project made an impact, or is likely to make an impact, on commercial technology or public use, including:

- *transfer of results to entities in government or industry;*
- *instances where the research has led to the initiation of a start-up company; or*
- *adoption of new practices.*

See above – REACH VA Parent will become a program offered by VA staff nationwide and Education webinars are available on YouTube

What was the impact on society beyond science and technology?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how results from the project made an impact, or are likely to make an impact, beyond the bounds of science, engineering, and the academic world on areas such as:

- *improving public knowledge, attitudes, skills, and abilities;*
- *changing behavior, practices, decision making, policies (including regulatory policies), or social actions; or*
- *improving social, economic, civic, or environmental conditions.*

Nothing to report.

- 5. CHANGES/PROBLEMS:** The Project Director/Principal Investigator (PD/PI) is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer whenever there are significant changes in the project or its direction. If not previously reported in writing, provide the following additional information or state, “Nothing to Report,” if applicable:

Changes in approach and reasons for change

Describe any changes in approach during the reporting period and reasons for these changes.

Remember that significant changes in objectives and scope require prior approval of the agency.

Nothing to report.

Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

Nothing to report.

Changes that had a significant impact on expenditures

Describe changes during the reporting period that may have had a significant impact on expenditures, for example, delays in hiring staff or favorable developments that enable meeting objectives at less cost than anticipated.

Nothing to report.

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Describe significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period. If required, were these changes approved by the applicable institution committee (or equivalent) and reported to the agency? Also specify the applicable Institutional Review Board/Institutional Animal Care and Use Committee approval dates.

Significant changes in use or care of human subjects

Nothing to report.

Significant changes in use or care of vertebrate animals.

N/A

Significant changes in use of biohazards and/or select agents

N/A

6. PRODUCTS: List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state “Nothing to Report.”

- **Publications, conference papers, and presentations**

Report only the major publication(s) resulting from the work under this award.

Journal publications. *List peer-reviewed articles or papers appearing in scientific, technical, or professional journals. Identify for each publication: Author(s); title; journal; volume: year; page numbers; status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

Please see attached documents:

- Final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 2)
- Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 3)
- Please see Dissemination Activities (Appendix 4)

Books or other non-periodical, one-time publications. *Report any book, monograph, dissertation, abstract, or the like published as or in a separate publication, rather than a periodical or series. Include any significant publication in the proceedings of a one-time conference or in the report of a one-time study, commission, or the like. Identify for each one-time publication: Author(s); title; editor; title of collection, if applicable; bibliographic information; year; type of publication (e.g., book, thesis or dissertation); status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

The REACH Parent Caregiver Notebook will be available for use in the VA.
See Appendix 4 – Dissemination Activities

Other publications, conference papers, and presentations. *Identify any other publications, conference papers and/or presentations not reported above. Specify the status of the publication as noted above. List presentations made during the last year (international, national, local societies, military meetings, etc.). Use an asterisk (*) if presentation produced a manuscript.*

Please see attached documents:

- Final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 2)
- Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans (Appendix 3)
- Please see Dissemination Activities (Appendix 4)

• **Website(s) or other Internet site(s)**

List the URL for any Internet site(s) that disseminates the results of the research activities. A short description of each site should be provided. It is not necessary to include the publications already specified above in this section.

Nothing to report

- **Technologies or techniques**

Identify technologies or techniques that resulted from the research activities. In addition to a description of the technologies or techniques, describe how they will be shared.

Nothing to report.

- **Inventions, patent applications, and/or licenses**

Identify inventions, patent applications with date, and/or licenses that have resulted from the research. State whether an application is provisional or non-provisional and indicate the application number. Submission of this information as part of an interim research performance progress report is not a substitute for any other invention reporting required under the terms and conditions of an award.

Nothing to report.

- **Other Products**

Identify any other reportable outcomes that were developed under this project. Reportable outcomes are defined as a research result that is or relates to a product, scientific advance, or research tool that makes a meaningful contribution toward the understanding, prevention, diagnosis, prognosis, treatment, and/or rehabilitation of a disease, injury or condition, or to improve the quality of life. Examples include:

- *data or databases;*
- *biospecimen collections;*
- *audio or video products;*
- *software;*
- *models;*
- *educational aids or curricula;*
- *instruments or equipment;*
- *research material (e.g., Germplasm; cell lines, DNA probes, animal models);*
- *clinical interventions;*
- *new business creation; and*
- *other.*

The six REACH Parent videos, Introduction and Post 9/11 Injuries Challenging Emotions and Behaviors, Caregiver Physical Health, Caregiver Emotional Health, Caregiver Social Support, and Red Flags and Review, are published on the Caregiver Center/REACH VA YouTube channel. While targeted to parents, these are relevant for any caregiver taking care of a service member or veteran with polytrauma, TBI, and/or PTSD. See Appendix 4 – Dissemination Activities.

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Provide the following information for: (1) PDs/PIs; and (2) each person who has worked at least one person month per year on the project during the reporting period, regardless of the source of compensation (a person month equals approximately 160 hours of effort). If information is unchanged from a previous submission, provide the name only and indicate “no change.”

Example:

Name: Mary Smith
Project Role: Graduate Student
Researcher Identifier (e.g. ORCID ID): 1234567
Nearest person month worked: 5

Contribution to Project: Ms. Smith has performed work in the area of combined error-control and constrained coding.
Funding Support: The Ford Foundation (Complete only if the funding support is provided from other than this award).

Name: Linda Nichols

Project Role: PI

Person month: 1.8

Contribution: Overall direction and approval, writing and editing of materials

Name: Jennifer Martindale-Adams

Project Role: Co-P, Co-II

Person month: 2.4

Contribution: Staff supervision, writing and editing of materials

Name: Jeffrey Zuber

Project Role: Data analyst

Person month: 6.0

Contribution: Development of data collection materials and databases, data integrity

Name: Carolyn Clark

Project Role: Research specialist

Person month: 12

Contribution: Writing and editing MOP and Parent Caregiver Notebook, recruiting, screening, c
enrolling, consenting, data collection

Name: Jessica Roxy Martin

Project Role: Interventionist/Program Coach

Person month: 6.0

Contribution: Recruiting, screening, enrolling, consenting, delivery of interventions

Name: John Chandler

Project Role: Research specialist

Person month: 12

Contribution: Recruiting, screening, enrolling, consenting, data collection

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

If the active support has changed for the PD/PI(s) or senior/key personnel, then describe what the change has been. Changes may occur, for example, if a previously active grant has closed and/or if a previously pending grant is now active. Annotate this information so it is clear what has changed from the previous submission. Submission of other support information is not necessary for pending changes or for changes in the level of effort for active support reported previously. The awarding agency may require prior written approval if a change in active other support significantly impacts the effort on the project that is the subject of the project report.

Nothing to report.

What other organizations were involved as partners?

If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe partner organizations – academic institutions, other nonprofits, industrial or commercial firms, state or local governments, schools or school systems, or other organizations (foreign or domestic) – that were involved with the project. Partner organizations may have provided financial or in-kind support, supplied facilities or equipment, collaborated in the research, exchanged personnel, or otherwise contributed.

Provide the following information for each partnership:

Organization Name:

Location of Organization: (if foreign location list country)

Partner’s contribution to the project (identify one or more)

- *Financial support;*
- *In-kind support (e.g., partner makes software, computers, equipment, etc., available to project staff);*
- *Facilities (e.g., project staff use the partner’s facilities for project activities);*
- *Collaboration (e.g., partner’s staff work with project staff on the project);*
- *Personnel exchanges (e.g., project staff and/or partner’s staff use each other’s facilities, work at each other’s site); and*
- *Other.*

Nothing to report.

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS: For collaborative awards, independent reports are required from BOTH the Initiating PI and the Collaborating/Partnering PI. A duplicative report is acceptable; however, tasks shall be clearly marked with the responsible PI and research site. A report shall be submitted to <https://ers.amedd.army.mil> for each unique award.

QUAD CHART: If applicable, the Quad Chart (available on <https://www.usamraa.army.mil>) should be updated and submitted with attachments.

RECRUITMENT AND RETENTION

CONSORT DIAGRAM

9. APPENDICES:

1. W81XH-17-C-0022 - Interventions for Parent Caregivers of Injured Military/Veteran Personnel Findings – Hypotheses and Aims
2. Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans. Manuscript in progress.
3. Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans. Manuscript submitted to The Gerontologist, June 2020.
4. Dissemination Activities

Interventions for Parent Caregivers of Injured Military/Veteran Personnel

Log #:14029002

Contract #:W81XWH-17-C-0022



PI: Linda Nichols

Org: Research, Inc/VA Memphis

Award Amount: \$1,258,621

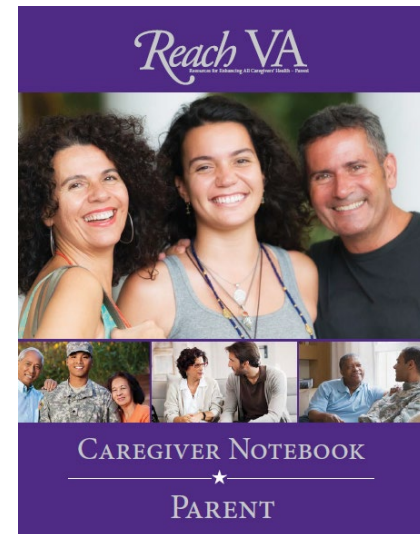
Study/Product Aim(s)

1. Determine effective strategies for providing education, skills building and support for parent caregivers;
2. Determine feasibility of conducting interventions with parent caregivers;
3. Determine characteristics of those recruited;
4. Determine satisfaction;
5. Determine commitment and adherence to therapeutic recommendations; and
6. Develop manuals for clinical translation.

Approach

Randomized clinical trial of 160 parent caregivers of combat wounded adult children, half in each arm. Compare 6 30 minute online webinars to 6 one-hour individual session, focusing on education, skills building and support over three months. Data collected at baseline, 3, and 6 months.

Accomplishments: 163 participants enrolled, randomized, and completed intervention, data analyzed, manuscripts in progress



Timeline and Cost

Activities	CY	17	18	19	20
Finalize materials, obtain approval, print materials					
Recruit subjects					
Administer interventions					
Collect, analyze, and process data					
Disseminate findings					
Estimated Budget (\$K)		\$210	\$419	\$420	\$210

Updated: June 25, 2020

Goals/Milestones

CY17-19 Goals Completed

- ☒ Obtain regulatory approvals
- ☒ Hire/train staff
- ☒ Develop materials
- ☒ Recruit, enroll, and randomize
- ☒ Administer interventions

CY18-CY20 Goals

- ☒ Collect, analyze, process data
- ☐ Disseminate findings

Comments/Challenges/Issues/Concerns

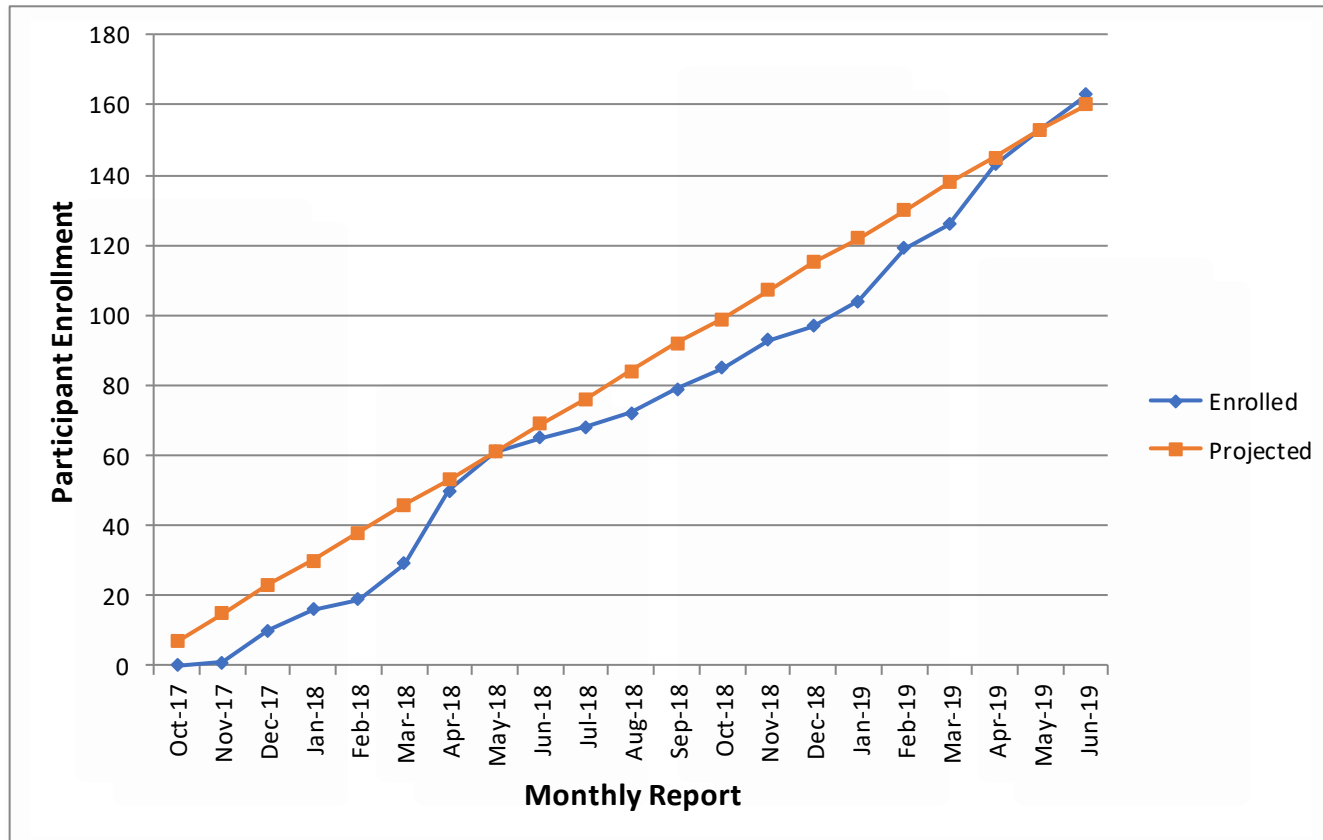
Budget Expenditure to Date

Projected Expenditure: \$1,258,621

Actual Expenditure: \$920,464.58

Recruitment and Retention

W81XWH-17-C-0022



Percent of participants that complete study

90.2%

W81XWH-17-C-0022 CONSORT Diagram

4/1/17 – 3/31/20

Enrollment

Assessed for eligibility (n=226)

Excluded (n=63)

- Not meeting inclusion criteria (n=29)
- Declined to participate (n=17)
- Other reasons (n=17)

Randomized (n=163)

Allocation

Allocated to REACH intervention (n=82)
• Received allocated intervention (n=78)
• Did not receive allocated intervention (attended no sessions) (n=4)

Allocated to Webinar intervention (n=81)
• Received allocated intervention (n=64)
• Did not receive allocated intervention (watched no modules) (n=17)

Follow-Up

Lost to follow-up (refused contact) (n=7)
Discontinued intervention (no longer caregiver n=2, care recipient death n=1, too busy n=1) (n=4)

Lost to follow-up (refused contact) (n=3)
Discontinued intervention (caregiver illness n=1, study not helping n=1) (n=2)

Analysis

Analysed (n=82)
• Excluded from analysis (n=0)

Analysed (n=81)
• Excluded from analysis (n=0)

Appendix 1

W81XH-17-C-0022 - Interventions for Parent Caregivers of Injured Military/Veteran Personnel

Findings – Hypotheses and Aims

Hypotheses:

1. Education Webinar arm participants will improve during the course of the study on outcomes, including depression, anxiety, and burden.

During the six month course of the study, Education Webinar arm participants showed significant improvement in depression, anxiety, and burden. (See Appendix 2, final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, Table 2.)

2. REACH (Resources for Enhancing All Caregivers' Health) individual sessions, compared to Education Webinars, will be more effective in improving outcomes, including depression, anxiety, and burden.

During the six month course of the study, there was no group by time significant difference between REACH VA and Education Webinar arms. (See Appendix 2, final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, Table 2.)

The effect of potentially confounding variables will be controlled for in analysis, i.e., determining whether impact is equivalent for participants who differ on a range of variables.

There was no difference in outcomes after controlling for WHODAS function score, baseline Veteran aggression, PTSD diagnosis, caregiver age, caregiver sex, income, and hard to pay for basics. Controlling for total social support caused a significant group by time effect ($p=.044$) for anxiety. Controlling for caregiver race caused the social support group by time effect to be non-significant ($p=.154$); however, race made no substantive difference in other results.

Table 2 from Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans.

Mixed Model Analysis of Outcome Variables

Variable	Baseline <i>M (SD)</i>	3 Months <i>M (SD)</i>	6 Months <i>M (SD)</i>	Group <i>p-value</i> ^a	Time <i>p-value</i> ^a	Group by Time <i>p-value</i> ^a
Depression, PHQ-9 (0-27)				.222	<.001	.399
REACH	6.0 (4.3)	4.6 (3.5)	4.4 (3.4)			
Webinar	7.3 (5.8)	6.5 (5.4)	6.3 (4.9)			
Anxiety, GAD-7 (0-21)				.772	.008	.100
REACH	6.6 (4.7)	5.2 (3.7)	5.3 (4.3)			
Webinar	7.2 (4.6)	6.7 (5.2)	6.8 (5.1)			
Burden, ZBI (0-48)				.138	<.001	.576
REACH	15.7 (8.6)	13.0 (8.5)	13.4 (8.5)			
Webinar	17.9 (8.9)	16.0(8.7)	16.1 (9.7)			
Veteran behaviors (0-31)				.543	<.001	.910
REACH	13.8 (5.4)	12.3 (5.1)	11.9 (5.4)			
Webinar	14.4 (5.4)	12.9 (6.1)	12.6 (6.1)			
Bothersome behaviors (0-31)				.386	<.001	.001
REACH	12.3 (6.0)	8.6 (5.9)	6.5 (5.7)			
Webinar	13.0 (6.1)	9.9 (6.9)	10.1 (7.0)			

Note. *N* = 163 and *n* = 82 for REACH and 81 for Webinar.

Specific Aims:

- 1) Determine effective strategies for providing education, skills building and support for stressed and burdened parent caregivers of injured returning service members;

In this study comparing two interventions for parent caregivers of their wounded, injured, and/or ill adult children veterans, both interventions provided benefit. During the six month course of the study, participants in both arms, six hour long individual sessions and six 30 minute online education webinars, showed significant improvement in depression, anxiety, burden, troubling veteran behaviors, and bothersome behaviors. (See Appendix 2, final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, Table 2.)

- 2) Determine feasibility of conducting interventions with parent caregivers.

Only four of the 72 Education Webinar arm participants said the project was too much work and 31% said they liked everything. Two of the 74 REACH arm participants reported the project was too much work and 51% said they liked everything.

- 3) Determine characteristics of those recruited;

Parents, on average, had been caregivers for 6.6 years and daily spent 7.7 hours providing care and 17.2 hours on duty. Parents were mainly mothers with average age 60.2 years. Average burden score approached high, and average depression, anxiety, frustrations, and somatization scores were mild. The veterans had functional limitations; they could not fully carry out daily activities for an average of 16.7 days/month, and only 9.2% were employed. Caregiver burden was related to veteran TBI diagnosis, aggressive behavior toward others, and functional limitations. Few parent caregivers were working full-time (22.7%); 85.3% had decreased personal spending, 84.0% dipped into personal savings, and 58.9% reduced retirement saving. There were two significant differences between participants in the two arms in race and ethnicity. There were more white caregivers in the webinar arm and more African American caregivers in the REACH arm. None of the six Hispanic/Latino caregivers were randomized to the Education Webinar arm. (See Appendix 3, baseline data manuscript submitted to *The Gerontologist* - Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans and Appendix 2, final report manuscript - Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, Table 1.)

Table 1 from Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

Caregiver and Veteran Demographics (n = 163)

Variable	Caregivers <i>M (SD)</i> or %	Veterans <i>M (SD)</i> or %
Female	89.6	14.7
Age, years	60.2 (6.8)	34.5 (6.4)
Marital status, married	57.1	6.7
Marital status, never married	7.4	54.0
Marital status, divorced/separated	25.2	38.6
Race, White	79.1	
Race, African-American	16.0	
Ethnicity, Hispanic/Latino	3.7	
Education, years (range 4-17)	14.0 (1.8)	
Had military service	12.3	
Caregiving duration, years (range <1-16)	6.6 (3.8)	
Live with parent		73.0
Have children		40.5
Employed, full-time		4.3
Employed, part-time		4.9
Military service, years (range <1-36)	6.7 (5.0)	
Military branch, Army	58.3	
Military branch, Marines	14.7	
Military branch, Navy	14.1	
Military branch, Air Force	12.3	

Table 2 from Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

Caregiver Financial/Career (n = 163)

Variable	<i>M (SD) or %</i>
Household income, monthly, US \$, median (IQR)*	4,167 (4300)
Care expenses, monthly, US \$, median (IQR)	350 (600)
Care expenses, % of income, US \$, median (IQR)	8.3 (17.7)
Cut back on personal spending	85.3
Dip into personal savings	84.0
Reduced retirement saving	58.9
Take out loan	46.0
Dip into retirement savings	30.1
Cut back on health spending	29.4
Financial strain (0-4)	2.9 (1.5)
Employed, full-time	22.7
Employed, part-time	16.6
Go in late, leave early	55.8
Give up working entirely	49.1
Take leave of absence	37.4
Lose job benefits	32.5
Go from full to part time	29.4
Take early retirement	27.0
Turn down a promotion	15.3

*Interquartile range

Table 3 from Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

Caregiver Well-Being and Health (n = 163)

Variable	<i>M (SD) or %</i>
Depression, PHQ-9 (0-27)	6.6 (5.2)
Anxiety, GAD-7 (0-21)	6.9 (4.7)
Burden, ZBI (0-48)	16.8 (8.8)
Caregiving frustrations (0-4)	0.8 (0.8)
Caregiver time providing care/day, hours	7.7 (4.5)
Caregiver time on duty/day, hours	17.2 (7.8)
General stress (1-10)	5.2 (2.3)
Overwhelmed	96.3
Frustrated	87.7
Cry	77.3
Lonely	65.0
Feel cut off	54.0
Total social support (0-30)	16.0 (5.8)
Received support (0-9)	2.8 (2.1)
Satisfaction with support (0-9)	4.2 (2.9)
Negative support (0-12)	3.0 (2.7)
General health (0-4)	2.1 (0.8)
Symptoms and severity (0-30)	8.3 (4.4)
Self-care (0-14)	8.6 (2.4)
Receiving counseling or support services	42.3

Table 4 from Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

Veteran Function (n = 163)

Variable	M (SD) or %
Diagnoses	
PTSD	80.4
TBI	58.9
Physical injuries	56.4
Mood disorder	22.7
Psychoses	13.5
ADL (0-6)	1.7 (2.0)
IADL (0-8)	6.5 (1.3)
WHODAS (0-128) ^a	61.2 (22.9)
Cognition (0-24)	11.3 (5.3)
Mobility (0-20)	7.7 (6.3)
Self-care (0-16)	5.5 (4.6)
Getting along (0-20)	9.3 (4.8)
Life activities (0-16) ^a	10.7 (4.4)
Participation (0-32)	16.9 (6.2)
Days unable to carry out activities	9.5 (10.3)
Days cut back on activities	7.2 (6.9)
Days symptoms present	28.3 (5.2)
Troubling behaviors (0-31)	14.1 (5.4)
Bothersome behaviors to caregiver (0-31)	12.7 (6.0)
Safety risks	
Concern that veteran has access to gun	3.7
Concern that veteran drives	18.4
Concern about veteran use of alcohol, prescription or illegal drugs	25.2
Veteran engaged in aggression or violence toward others	30.7
Concern about veteran harming self	20.2
Concern about veteran harming others	10.4

^a Calculated without work/school questions because sample had so few working or in school

Table 5 from Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

Comparison between Caregivers of Veterans with and without Aggression

Variable	Aggression (n = 50)		No Aggression (n = 113)		p^a	d
	M	SD	M	SD		
Depression, PHQ-9 (0-27)	8.3	5.8	5.9	4.7	.007	0.47
Anxiety, GAD-7 (0-21)	9.0	4.8	6.0	4.3	<.001	0.67
Burden, ZBI (0-48)	19.9	9.2	15.4	8.3	.002	0.53
Caregiving frustrations (0-4)	1.2	0.8	0.6	0.7	<.001	0.80
Time providing care (hours/day)	7.1	4.4	7.9	4.5	.325	0.20
Time on duty (hours/day)	18.3	7.5	16.8	8.0	.240	0.17
General stress (0-10)	5.9	2.2	4.9	2.2	.006	0.48
Total social support (0-30)	14.5	5.2	16.7	5.9	.025	0.39
Somatization, PHQ-15 (0-30)	9.2	4.6	7.8	4.3	.063	0.32
Behaviors (0-31)	16.4	4.2	13.1	5.6	<.001	0.64
Bothersome behaviors (0-31)	15.6	4.3	11.4	6.3	<.001	0.72

^a Statistical comparisons were independent samples t-tests.

4) Determine satisfaction;

There were several significant differences between the study arms in terms of caregiver reported benefit. Caregivers in the REACH arm, compared to the Webinar arm, were more satisfied with the format of the intervention ($p = .021$) and reported significantly more overall satisfaction ($p = .001$).

Caregivers reported several kinds of benefit including resources, self-reflection, not feeling alone, new skills, improved self-efficacy, and (in smaller numbers) helping others. They reported financial and legal issues and difficulty in obtaining care as barriers to care. Unmet needs included parent-specific resources and early access to resources and resources and planning for care for their child in the future when they were no longer able to care. (See Appendix 2, final report manuscript – Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans, Table 3.)

Table 3 from Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans.

Benefit Themes Reported by Participants

Theme	Examples
Resources	Talking to a live person with knowledge. I think of the program coach as a "catalyst," she got me to think about things in a certain way. Having a person to assist and to guide." Opened up areas, brought them to mind. Things I hadn't focused on. (Program Coach) was a pleasure, very empathetic. Helped me focus on addressing problems. She helped me prioritize. I think the webinars were really good. Some went into explanation of PTSD and TBI, the symptoms, signs, how to react to them. Anybody with a loved one with these issues. This should be handed out to them. Would've been so helpful in the beginning. The study...gives me the right techniques, ways, and strategies in dealing with a person like my son with special needs. I also learned more about his mental illness. I didn't understand his lack of decision-making. That just didn't make sense to me. Now I understand more...I've learned better ways to deal with my son and try to stay positive.
Self-reflection	It made me look at things from a different perspective...Made me get out of my old habits and think of things in a new way. The questions asked made me realize I'm not the only one going through these things. He has asked us for a gun, and I keep saying No. Good to know I'm doing the right thing. Until you asked these questions, I never thought about how my son affects my social life. Being able to reflect and move forward...These questions make me realize I'm doing a good job.
Someone cares/not alone	It's helpful to know that someone cares about me and my son. I feel not alone. Makes me feel like myself. I'm not the only one going through this. What he (Veteran) does is normal. Knowing I'm not alone, not the only one feeling this way really helped me. Program coach was informative and caring, which is significant to an isolated parent.
Skills - Coping, Relaxation, Communication,	Really liked the deep breathing and mindfulness. I'd never done that. Really worked for me. It helped both me and my daughter, especially our communication.

Problem Solving	It helped me sharpen up on my listening skills. Helps you come up with solutions or seek out solutions.
Self-efficacy	Put together a Caregiver plan to take care of myself. Helped me to see the need to take care of myself. It taught me to be a good Caregiver and be more supportive...I feel more confident as a Caregiver. I am keen to correct what I thought I was doing well, and when studying and reading, this is far from reality.
Helping others	My sincere desire is to help you do some research on Parents. I'm really just hoping to help other Parents. I initially enrolled in study to help the VA. Since I'm receiving services, I thought it would be good for me to help out. A lot of people at Camp LeJeune need this information. Stuff like this should be standard issue.

5) Determine commitment and adherence to therapeutic recommendations;

Caregivers in the REACH arm, compared to the Webinar arm, reported greater understanding of post 9/11 injuries and their effects on them ($p = .020$), greater ability to solve problems ($p = .011$), and greater overall coping skills ($p = .002$).

Caregivers in the REACH arm rated their efforts at problem solving by reporting whether the problem was a lot worse, a little worse, the same, a little better, or a lot better. Caregivers all identified and worked on one problem; some caregivers worked on more than one. A total of 57.4% of caregivers rated their first problem better; 30.7% rated it the same, and 12% rated it worse.

6) Develop manuals for clinical translation.

REACH VA programs are available to be delivered to caregivers of Veterans and Veterans who are caregivers across the VA health care system. Caregivers can be served from the VA's national Caregiver Center located at the Memphis VA Medical Center or at each VA facility. By September 30, each facility will have a trained and certified REACH VA individual sessions Program Coach and a REACH VA telephone support group Leader, who will be able to offer the REACH VA Parent program, using the Parent Caregiver Notebook and Risk Assessment and information for the Program Coach and Group Leader Manuals. These Coaches and Group Leaders are already able to offer programs for caregivers of those with PTSD, ALS, MS, dementia, and SCI/D. They also have materials for Post 9/11 Spouses and Caregivers of Any Veteran, Any Era. The Parent materials will be made available to each VA facility and will be used by them and the Caregiver Center to serve parent caregivers. (The REACH Parent Caregiver Notebook is described in Appendix 4 and is available to DoD upon request to the study Principal Investigator at linda.nichols@va.gov.)

In addition, the six REACH Parent webinars have been placed on the REACH VA YouTube channel. These 30-minute webinars include: Introduction and Post 9/11 Injuries, Challenging Emotions and Behaviors, Caregiver Physical Health, Caregiver Emotional Health, Caregiver Social Support, and Red Flags and Review. While targeted to parents, these are relevant for any caregiver taking care of a service member or veteran with polytrauma, TBI, and/or PTSD. (See Appendix 4 – Dissemination Activities.)

W81XH-17-C-0022 - Appendix 2

Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

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Declaration of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

Data

Data are available upon request. Data are in the Caregiver Center repository at the Memphis Veterans Affairs Medical Center.

ClinicalTrials.gov Identifier: NCT03309046

ABSTRACT

Background and Objectives.

Research Design and Methods. B

Results. Parents, on average, had been caregivers for 6.6 years and daily spent 7.7 hours providing care and 17.2 hours on duty. Parents were mainly mothers (average age 60.2 years). Average burden score approached high, and average depression, anxiety, frustrations, and somatization scores were mild. The veterans had functional limitations; they could not fully carry out daily activities for an average of 16.7 days/month, and only 9.2% were employed. Caregiver burden was related to veteran TBI diagnosis, aggressive behavior toward others, and functional limitations. Few parent caregivers were working full-time (22.7%); 85.3% had decreased personal spending, 84.0% dipped into personal savings, and 58.9% reduced retirement saving.

Discussion and Implications. These parent caregivers were taking care of functionally limited adult children at financial and career cost to themselves. As these parents and their adult children age, providing care and resources may present greater challenges for them, for the military and veteran care systems they rely on for support, and for society.

KEYWORDS: military, veterans, parenthood/parent-adult child relations, caregivers, families < education, cost/financing < long-term care, PTSD, TBI

WORD COUNT: 5478 (text and references)

Background and Objectives

With military personnel in Iraq and Afghanistan surviving what were previously fatal injuries (Allen & Resnik 2007; Christensen, et al., 2009), there is ongoing discussion about how to provide care for them and to support their families. The unique battlefield conditions in these conflicts have highlighted two challenging consequences – post-traumatic stress disorder (PTSD) and traumatic brain injury (TBI) (Christensen, et al., 2009). For veterans seen by the Department of Veterans Affairs (VA) during 2009-2011, 9.6% were diagnosed with TBI, 29.3% with PTSD, and 40.2% with pain. Of those with TBI, nearly half had both PTSD and pain diagnoses (Cifu et al., 2013). The Dole-Shalala Commission (United States President's Commission On Care, 2007) concluded that, “The most seriously injured service members and their families are embarking on a long journey together...” For unmarried service members, parents are an important part of that journey as they transition from active duty to veteran status.

For veterans with high intensity needs from polytrauma – TBI, post traumatic stress disorder (PTSD), and pain – 50% of their caregivers provide care for at least 80 hours a week (Griffin et al., 2014). These service members with high intensity needs require help with activities of daily living (ADL), such as bathing or feeding, and instrumental activities of daily living (IADL), such as shopping or managing finances. Even for veterans needing low and moderate intensity care, caregivers provide care from 5 to 80 hours a week. Moderate intensity care requires help with IADLs, and low intensity care requires assistance with complex tasks, i.e., help with benefit or health care system or emotional support (Griffin et al., 2014; Van Houtven et al., 2012). Caregiving continues after a polytraumatic injury. After four years, 22% of veterans still required assistance with ADLs and 48% with IADLS (Griffin et al., 2012).

Consequently, family members caring for an injured service member report high levels of caregiver burden and stress (Brancu, Straits-Tröster, & Kudler, 2011). Caregivers of veterans with high intensity needs, compared to moderate, report greater loneliness (Griffin et al., 2014). When the service member is suffering from polytrauma, caregiver burden increases substantially (Perlick et al., 2009). Caregivers put off addressing their own health needs often leading to depression and becoming burned out (Kreutzer et al., 2009; Shay & Burris, 2008).

Providing care for a veteran with PTSD or TBI can also have consequences for caregivers' well-being. Partners of veterans with PTSD, compared to those who do not have PTSD, report significantly more marital problems, more violence on the part of the veteran, more violence themselves, and lower levels of happiness and life satisfaction (Galovski & Lyons, 2004). TBI caregivers report high levels of distress, burden, and poor health (Delgado et al., 2018; Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013).

Carlson et al. found that caregivers with higher levels of depression, anxiety, or any physical health problems increased the chance of subsequent injuries to the patient (2012). Service members returning with TBI made less progress in treatment if the family unit was distressed (Dausch & Saliman, 2009). Conversely, PTSD symptoms often decrease as family and social support increases (Frain et al., 2010). Improving caregiver social support also improves outcomes for both (Griffin et al., 2009, Weaver et. al, 2009). Providing education and mental health resources to families can help reduce caregiver burden, which in turn positively affects the health of the care recipient (Bernhardt, 2009; Monson et al., 2009).

Consequently, there has been a call to provide services for caregivers of injured service members, including additional support (Griffin et al, 2009; Sayer et al., 2009; Wool & Messinger, 2012), education and counseling to decrease stress and increase coping skills

(Carlson et al., 2012; Dausch & Saliman, 2009; Friedmemann-Sanchez et al., 2008; Perlick et al., 2009), skills training and information about rehabilitation (Dausch & Saliman, 2009; Sayer et al., 2009), and education about the military system (Christensen et al., 2009; Griffin et al., 2009).

Despite this identified need and the potential benefits of helping caregivers, more research is needed to evaluate the effectiveness of caregiver interventions for this caregiving population (Boschen et al., 2007). Researchers and clinicians cite gaps in our knowledge of caregiving for these service members/veterans, including information on TBI caregiving (Dausch & Saliman, 2009) and what factors cause higher levels of anxiety and depression in TBI/PTSD/polytrauma caregivers (Ennis et al., 2013). Research is needed to determine strategies caregivers need to better care for themselves and their patients with polytrauma and TBI (Friedemann-Sanchez et al., 2008), communication methods between the caregiver and care recipient, and best practices to help families adjust (Griffin et al., 2009; Hazle, Wilcox & Hassan, 2012). Few TBI interventions exist for spouses and parents (Boschen et al. 2007; Sinnakarrupan & Williams, 2001). Although there is a growing body of knowledge on spouses providing care for post deployment reintegration, research should also look at parents' perceptions of changes within the family due to caring for a young adult with TBI (Wongyatunyu & Porter, 2008).

Finally, many families do not live near services that offer TBI treatment (Cote et al., 2007; Weaver et al., 2009) and there are not enough psychiatrists to meet the needs in rural or low income areas (Link & Palinkas, 2013). Providing services by phone or online may offer ways to reach families in isolated areas, which in turn may improve family outcomes (Griffin et al., 2009; Weaver et al., 2009). Providing more resources may provide more coping skills and resiliency leading to reduced anxiety and stress (Griffin et al., 2009; Link & Palinkas, 2013).

To meet this need, a randomized clinical trial tested two interventions to help parent caregivers: structured and targeted individual sessions offered by telephone and webinar education sessions.

Methods

Overview

REACH Parent was a three-year randomized clinical trial (RCT), April 2017 through March 2020, funded by the US Army Medical Research and Development Command (USAMRDC) Military Operational Medicine Research Program. Participants were parents of, and the main caregiver of, a post 9/11 veteran or service member with a diagnosis of TBI, PTSD, or physical injury and at least one ADL limitation or two or more IADL limitations. Parents had to provide 3 hours or more of care per day for at least 6 months and endorse at least 2 caregiving stress behaviors (overwhelmed, often needing to cry, angry/frustrated, cut off from family/friends, moderate/high levels of stress, and declining health). The study was conducted under the oversight of VA Medical Center (VAMC) Memphis Institutional Review Board (IRB) and USAMRDC Human Research Protection Office. Recruitment occurred through the VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC), which provides training, health care services, and a monthly stipend to eligible caregivers, and military/veteran family websites and social media. After telephone screening, a consent form was mailed to the potential participant for an informed consent call, followed by telephone baseline data collection upon receipt of the signed consent.

Interventions

Study arms were: Resources for Enhancing All Caregivers' Health in the VA (REACH VA) individual sessions, which are delivered by telephone and are structured and targeted; and webinar education sessions providing information on polytrauma and caregiving.

REACH. The REACH VA caregiving intervention has been shown to decrease caregiver depression, burden, frustrations, and the number of challenging behaviors/symptoms reported for veterans with dementia (Nichols et al., 2011; 2016). The intervention for this study, delivered by telephone, included 6 one-hour sessions during 3 months. Originally developed for caregivers of individuals with dementia, the program has been expanded to include spinal cord injury/disorders, multiple sclerosis, amyotrophic lateral sclerosis, and PTSD caregivers. For this study, polytrauma, PTSD, and caregiving subject matter experts (SMEs), including clinicians, researchers, and caregivers, tailored the intervention, specifically the Risk Assessment and Caregiver Notebook. For the Risk Assessment, certain topics are standard questions/risks for all caregivers (e.g., depression, burden, physical well-being concerns such as sleep and exercise) and are not modified. Specific safety risks and care recipient concerns or troubling behaviors are developed by the SMEs. For example, for the Parent Risk Assessment, concern about access to a gun and concern about substance use were both identified safety risks.

The Caregiver Notebook has short chapters with practical strategies and resources. The SMEs provided polytrauma and parent focused examples for the 17 caregiving stress and coping chapters (e.g., family roles, healthy lifestyle, communicating with health care providers). The 17 care recipient issues or care challenge chapters on such topics as blast related injuries, accessibility and equipment, sleeping, and socializing were developed by the SMEs.

Based on a stress health process model (Cohen, Kessler, & Gordon, 1995; Lazarus and Launier, 1978), REACH helps caregivers manage patient behavioral concerns and their own

stress. It is structured through a manual that specifies activities to occur at each session to ensure that the main caregiving risk areas are covered, including information on the disease and its course, safety for the care recipient, caregiver health and physical and emotional well-being, social support, and management of care recipient problem behaviors. The Risk Assessment targets specific concerns of the caregiving dyad within each caregiving risk area. The two REACH Parent Coaches, masters' level educator and psychologist, were trained during a standardized three-hour class and certified by a knowledge test and by performing role plays of problem solving and mood management. The Program Coach taught problem solving, stress management techniques, and mood management/cognitive reframing to think differently about situations that cannot be changed.

Webinars. The six 30-minute long Educational Webinars could be viewed at any time and as many times as the participant wished during a three month window. Topics included

- Introduction and Post 9/11 Injuries – common injuries; VHA health care team, accessibility and mobility; hygiene; safety concerns; and technology assistance
- Challenging Emotions and Behaviors for the Veteran – emotional issues; communication; sleep; pain, substance abuse; social avoidance; hygiene; overspending; depression
- Caregiver Physical Health – healthy lifestyle; exercise; sleep; appointments; nutrition; finances and legal; benefits and resources; navigating the system; communicating with health care providers; family roles; interdependence; taking care of you; personal goals
- Caregiver Emotional Health – Stages of loss and grief; coping; communication; patience; feelings; goals; support groups; feeling unappreciated; miscommunication; depression
- Caregiver Social Support – barriers to support; making friends; asking for help; online resources; self-reliance; de-stressing; self-talk; significant other relationships; socializing;

- Red Flags – guide for unsafe or dangerous behaviors; safety plan for red flag behaviors; firearms; suicide prevention; dealing with anger; domestic violence; abuse

Data

All data are caregivers' self-reports. Data were collected by trained interviewers by telephone at baseline and three and six months.

Caregiver and veteran demographics. Sex, age, marital status, race/ethnicity, employment status, and military service were collected for both caregivers and veterans. Education and caregiving duration were collected for caregivers. For veterans, living arrangement, children, and military branch were collected. Household income was assessed.

Outcomes – caregiver well-being and health. The Patient Health Questionnaire (PHQ-9) was used to assess depression (Kroenke, Spitzer, & Williams, 2001). The PHQ-9 has nine items based on the DSM-IV depression diagnostic criteria that are scored from 0 (not at all) to 3 (nearly every day). Cut points for depression are <5 (minimal), <10 (mild), <15 (moderate), <20 (moderately severe), or ≥ 20 (high/severe). The PHQ-9 has acceptable diagnostic properties for detecting major depressive disorder for cut-off scores between 8 and 11 (Manea, Gilbody, & McMillan, 2012). PHQ-9 Cronbach's alpha is .86 (Kroenke, et al., 2001).

The Generalized Anxiety Disorder (GAD-7) scale was used to assess anxiety. This 7-item symptom checklist demonstrates good performance in detecting generalized anxiety disorder, panic disorder, social anxiety disorder, and PTSD (Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007; Spitzer, Kroenke, Williams, & Löwe, 2006). GAD-7 sensitivity is .89 and specificity is .82 (Spitzer et al., 2006). Scoring for each item ranges from 0 (not at all) to 3 (nearly every day) for a summed score of 0 to 21, higher scores indicating more anxiety. Cut

points of 5, 10, and 15 represent mild, moderate, and severe levels of anxiety (Spitzer et al., 2006).

Caregiver burden was assessed using the 12-item Zarit Burden Interview (ZBI) short version (Bédard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980). Items are scored 0 (never) to 4 (nearly always), with higher scores indicating greater burden. A summed score of ≥ 17 indicates severe/high burden (Stagg & Lerner, 2015). ZBI Cronbach's alpha is .85 for a sample (N = 1095) of Canadian dementia caregivers (O'Rourke & Tuokko, 2003).

Veteran behaviors and bother with behaviors. In the development of the intervention the subject matter experts identified thirty-one potentially troubling behaviors that might be challenges for the caregiver, such as physical and functional difficulties, cognitive/affective concerns, and behavioral concerns. Caregivers rated as 0 (absent) or 1 (present) during the past month. For each behavior present, the caregiver was asked about bother or concern. Both presence of troubling behaviors and behaviors that are bothersome/concerning are summed to produce scales with scores ranging from 0 to 31, with higher scores signifying more behaviors and more bothersome behaviors. Cronbach's alpha is .80 for behaviors and .85 for bothersome behaviors.

Benefit and satisfaction. At 6 months, both caregivers were asked if they had benefited from the program and from each intervention. Caregivers were asked to rank degree of benefit and confidence on a scale from not at all (1) to extremely (5). Caregivers were also asked qualitative open-ended questions about usefulness of the interventions, focusing on satisfaction, benefit, and utility. In addition, parents were invited to share any additional information (advice, lessons learned, your personal Caregiving story, resources, things that would help you as a Caregiver, etc.) Caregivers were also asked about barriers to care.

Analysis

The chief quantitative data analysis strategy was intention-to-treat, with participants analyzed according to initial arm assignments. Baseline characteristics were compared between participants in each arm using chi-squared test or independent t-test, as appropriate. For outcomes, randomization arms were compared using repeated measures mixed linear models to estimate group by time interaction. P values ≤ 0.05 were considered statistically significant. The study was designed to provide statistical power of 0.80 to document as statistically significant a true population difference in intervention effect equal to at least 0.25 SD of a primary outcome variable.

For qualitative analysis, parent responses were examined individually by three anthropologist staff members, all with prior experience in coding of qualitative data. The goal was understanding of participants' descriptions of benefit and barriers, without prior conceptualizations of what they might be (Glesne, 1999). Each reviewer sorted the descriptions, concepts and central ideas into potential themes (Bernard, 2006; Maxwell, 1996) using the scrutiny techniques of repetitions and similarities and differences (Glaser & Strauss, 1967; Ryan & Bernard, 2003), which were then agreed upon by the reviewers. Topics that occurred repeatedly were linked to verbatim quotes (Bernard, 2006).

Results

Participants

A total of 226 caregivers were assessed for eligibility; of the 63 who were not eligible, 46% did not meet eligibility criteria, 27% declined, and 27% were excluded for other reasons, such as not responding after screening (**Figure 1**).

There were 162 parent caregivers of a veteran adult child who was wounded, ill, and/or injured plus one caregiver of an active duty service member who was transitioning from active duty (**Table 1**). Parent caregivers were mostly mothers (89.6%) with average age of 60.2 years; 57.1% were married. Average length of caregiving was seven years. Many (90.2%) were participating in the VA's PCAFC. The veterans were mostly male (85.3%) with average age of 34.5 years (**Table 1**). Few (9.2%) were employed full or part time, and 73% lived with their parent. Only 6.7% were married and 54.0% were never married. Caregivers and veterans have been extensively described elsewhere (baseline paper). There were more white caregivers in the webinar arm and more African American caregivers in the REACH arm. None of the six Hispanic/Latino caregivers were randomized to the Education Webinar arm.

Outcomes

During six months, participants in both arms improved significantly for all outcomes, both caregiver well-being outcomes of depression, anxiety, and burden and veteran behaviors and bothersome behaviors (**Table 2**). There was a group by time difference for bothersome behaviors. The effect of potentially confounding variables was examined. There was no difference in outcomes after controlling for WHODAS function score, baseline Veteran aggression, PTSD diagnosis, caregiver age, caregiver sex, income, and hard to pay for basics. Controlling for total social support caused a significant group by time effect ($p=.044$) for anxiety. Controlling for caregiver race caused the social support group by time effect to be non-significant ($p=.154$); however, race made no substantive difference in other results.

Participant Benefit

There were several significant differences between the study arms in terms of caregiver reported benefit. Caregivers in the REACH arm, compared to the Webinar arm, were more

satisfied with the format of the intervention ($p = .021$) and reported significantly more overall satisfaction ($p = .001$). They also reported greater understanding of post 9/11 injuries and their effects on them ($p = .020$), greater overall coping skills ($p = .002$), and greater ability to solve problems ($p = .011$). Caregivers in the REACH arm rated their efforts at problem solving by reporting whether the problem was a lot worse, a little worse, the same, a little better, or a lot better. Caregivers all identified and worked on one problem; some caregivers worked on more than one. A total of 57.4% of caregivers rated their first problem better; 30.7% rated it the same, and 12% rated it worse.

Several kinds of benefit were reported by participants including resources, self-reflection, not feeling alone, new skills, improved self-efficacy, and (in smaller numbers) helping others (**Table 3**). The most mentioned benefit was resources, and caregivers in the REACH arm mentioned resources more often than caregivers in the webinar arm. Caregivers felt the resources available to them throughout the study were beneficial, including the sessions and webinars, education, and the Caregiver Notebook. Caregiving assessment batteries are often an opportunity for self-reflection. Caregivers used the questions to think about their own caregiving situations, usually in a new or different way. Caregivers also felt by participating in the study that they were not alone and that someone cared about them.

Caregivers learned skills that they were able to use to be better caregivers and to improve the caregiver/care recipient relationship. The main skills mentioned were coping, relaxation, communication, and problem solving. Caregivers felt they had improved their self-efficacy. They used the information given or questions asked to make changes in order to be better caregivers. Caregiver specifically mentioned taking care of themselves; seeking or achieving

improvement as a caregiver, having an improved outlook, and moving forward. Finally, caregivers hoped that their participation would help other caregivers and the VA.

Barriers to Care and Unmet Needs

There were two main barriers to care that parents perceived – financial and legal issues and difficulty in obtaining care. Parent caregivers reported previous and/or current financial and legal issues they have dealt with, including those related to their child and those related to their own concerns. Veteran-related issues included their adult child veteran being arrested due to mental health issues, child support issues for the veteran’s children, and the veteran spending too much money due to mental health issues. As one mother reported, *“He spends every cent he gets. He told me that he feels like he is going to die soon so he lives like every day is his last. We just can't keep living this way.”* For the parent caregivers, there are immediate financial concerns, *“I don't have transportation to get him there because our rent went up, and we don't have money to move,”* and longer term financial concerns, *“My biggest concern is I quit my job to take care of my son. My wife and I haven't been paying into social security. What's going to happen to us in the future?”*

Parents reported struggling to obtain care for their adult children veterans. They reported difficulty communicating with the VA and navigating the VA system, specifically referencing communication difficulties - between VA facilities, between VA and outside vendors, and between VA and DOD. As one caregiver reported, *“Navigating the systems of insurance and the VA is very challenging.”* Another wished for, *“...better education for Parents from the DoD early on and awareness of things to come in the future. Need to know what to look for and what to do. Better liaison between DoD and VA would make life less complicated.”*

However, when the system works, it works well. *“I meet with them (Caregiver Support Group) once a month. It's great. Focused on caregivers' needs. My son has received the care he's needed when he needed it. The VA gets a bad rep in the news, but you won't hear that from us. There are plenty of resources available if you need them.” “Local caregiver support is really good. A lot of pressure is being taken off of us. I really appreciate it.”*

Although resources were the main benefit mentioned from the study, parents wanted still more access to resources, specifically parent-specific resources as many resources are geared toward spouses. As one caregiver said, *“I've never gotten any support as a Parent Caregiver.”* Parents also would like earlier access to resources, at the beginning of caregiving, *“New families really need this especially with finding resources. We didn't get any resources. We had to figure it out on our own. It was very hard in the beginning. We ended up moving closer to family.”* Parents specifically mentioned the REACH intervention. *“It would be helpful for all parent caregivers to have this available. It would be very helpful if they all had to go through a 3-month thing like this.”* Parents hoped for resources for, and awareness of, invisible wounds (addiction, mental illness, military sexual trauma, traumatic brain injury). This often leads to increased caregiver burden (social, family, emotional strain). *“The invisible wounds are really hard. People don't understand. They look at him weird and think he's a young man. Why can't he just get a job?... He's a different person. The family doesn't understand. My other son doesn't even talk to us.”*

Finally, parents are worried about the future and what is going to happen to their adult children once they can no longer provide care. As one parent said, *“...what will happen to him long-term? I'm old. What's going to happen to him when I can't care for him?”* Another

commented, *“He will be 38 years soon, and we are retiring. We would prefer he have some independence, but he doesn't exhibit responsible behavior.”*

Discussion and Implications

In this study comparing two interventions for parent caregivers of their wounded, injured, and/or ill adult children veterans, both interventions provided benefit. During the six-month course of the study, participants in both arms, hour long individual sessions and 30-minute online education webinars, showed significant improvement in depression, anxiety, burden, troubling veteran behaviors, and bothersome behaviors. Caregivers reported several kinds of benefit including resources, self-reflection, not feeling alone, new skills, improved self-efficacy, and helping others. They reported financial and legal issues and difficulty in obtaining care as barriers to care. Unmet needs included parent-specific resources, early access to resources, and resources and planning for care for their child in the future when they were no longer able to care.

There were study limitations that should be mentioned that may have influenced results. Caregiver had been providing care for an average of 6.6 years, with a range of 1 to 16 years. Many caregivers reported that they needed this type of help early on in their caregiving, but they had now resolved many of their initial concerns. One study limitation is that all data are by caregiver self-report. Another study limitation is the potential threat to generalizability of the study sample. Over 90% of the parent caregivers were participating in the VA's PCAFC, which means they were taking care of a veteran who has been clinically determined to need a full-time caregiver. Other veterans or service members receiving care from their parents may not be as severely wounded ill or injured. There may be some other type of difference that is not known

between caregivers participating in this program and in other caregivers, the additional VA stipend for these caregivers, for example.

Implications

Based on our findings, there are several recommendations that could help parent caregivers of their wounded, ill, and/or injured adult children, if implemented by the Department of Defense and the Department of Veterans Affairs. These recommendations are related to education and assistance, access, and services, and all were voiced by the parent caregivers.

Parents need education at the transition from the military. They need to understand their children's injuries and conditions, including invisible wounds, possible sequelae, and prognosis. As parents may not be the primary caregiver at the time of the veteran's transition, they could be included with spouse caregivers. They could also be provided with online instruction. Parents also need education about and help with financial and legal documents, such as Powers of Attorney; eligibility forms; fiduciary documents; compensation and pension decisions about service eligibility; and grants for home renovations. Recommendations include:

- Provide access to the REACH Parent webinars or similar materials for Parent Caregivers, expanding topics to include specific DoD and VA financial and legal provisions.
- Offer REACH Parent behavioral intervention to Parent Caregivers.
- Encourage Parent Caregivers to consult local resources (and help steer them to appropriate resources) for help. For example, for older caregivers, local Area Agencies on Aging help caregivers understand and fill out living wills, powers of attorney, and other legal and financial documents.

- Provide one person (and that person's contact information) for each new Parent Caregiver who will act as a point of contact for all questions and concerns. This may reduce the frustration and inconsistency that Parent Caregivers expressed in this study.

Parents and families are not always included in briefings and do not have access to the same benefits, support, and resources as spouses.

Recommendations:

- Consider extending some spousal privileges to Parent Caregivers, particularly access to mental health care.
- Offer counseling and face-to-face or telephone support groups for Parent Caregivers and other family members of the injured service member. Include care/support group for the Veteran (and childcare, if needed), so caregivers may attend.
- Encourage Vet Centers to include services for Parent Caregivers.
- Access to military bases so Parent Caregivers may shop for the Service Member at the commissary and get prescriptions at the base pharmacy.

Parents fear what will happen to their children once they are no longer able to provide care. Aging Parent Caregivers need to know that their children will be cared for once they have died or can no longer provide care. Nursing homes currently do not provide age-appropriate interaction for these younger Veterans. Recommendations include:

- VA and DoD working together to create a long-term plan for these Veterans.
- Group home model for younger Veterans with activities could work; consider VA's Medical Foster Home Program.

These are also recommendations from the Elizabeth Dole Foundation (Ramchand et al., 2014; Taniellian et al., 2017). Their recommendations include building caregivers' skills and confidence and mitigating the potential stress and strain of caregiving by making effective programs widely available, which the parent caregivers called for with the availability of interventions. The Dole recommendations to acknowledge caregivers' special needs and status and make programs available to caregivers through reframing eligibility for programs echo parents' requests to be considered in benefits and programs that now exclude them. The parent caregivers' fears of the future is seen in the Dole recommendation to ensure the long-term wellbeing of caregivers and the agencies that support them to anticipate the needs of future military caregivers in a changing political and fiscal environment.

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Figure 1. Sampling and Flow of Participants through REACH Parent

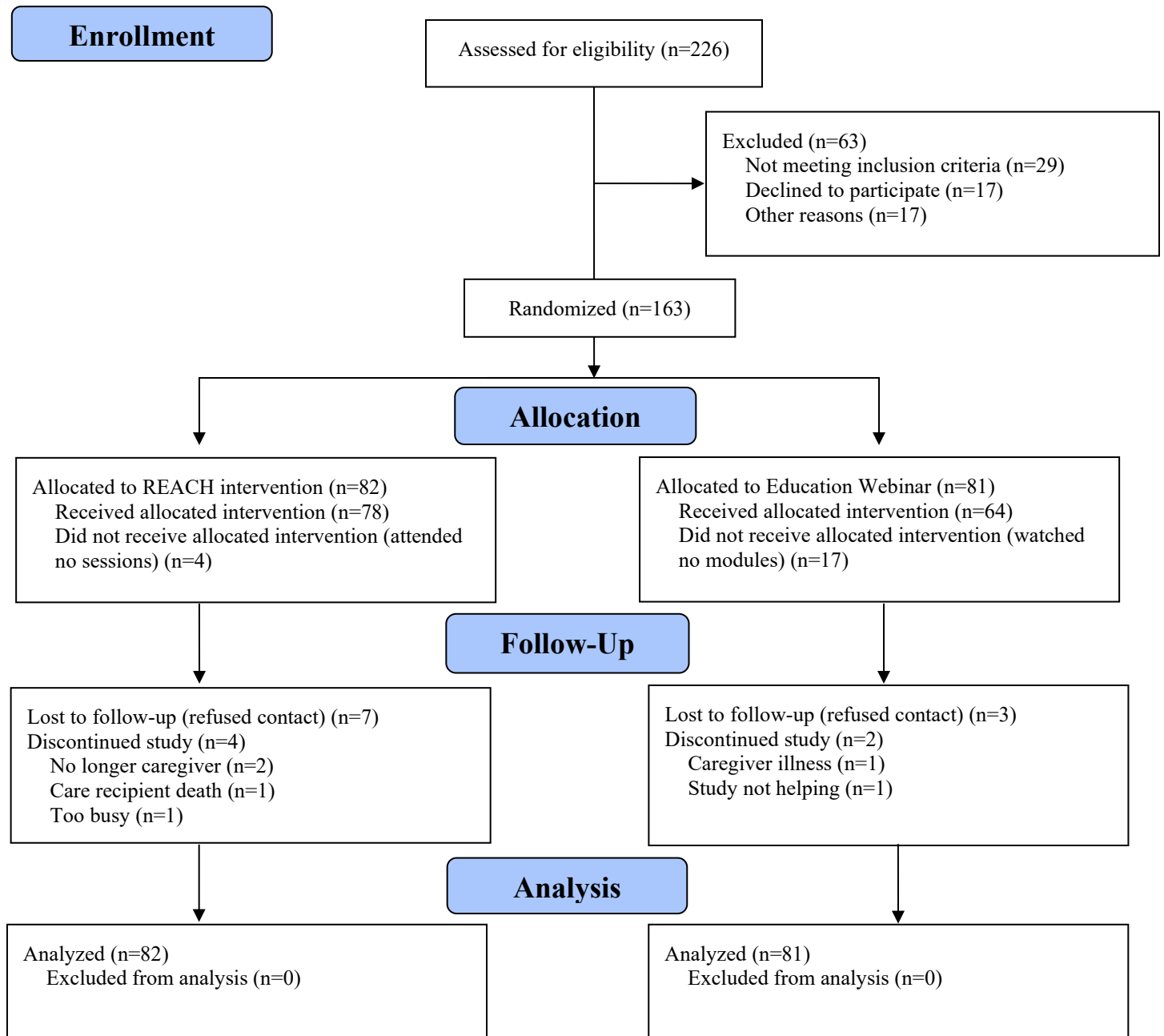


Table 1.

Demographics of Parent Caregivers and Veterans

Variable	Total n = 163 <i>M (SD) or %</i>	REACH n = 82 <i>M (SD) or %</i>	Webinar n = 81 <i>M (SD) or %</i>
Caregivers			
Female	89.6	90.2	88.9
Age, years	60.2 (6.8)	60.2 (7.3)	60.1 (6.3)
Marital status			
Married	57.1	62.9	51.2
Never married	7.4	9.8	4.9
Divorced/separated	25.2	25.6	24.7
Widowed	10.4	13.4	7.4
Race*			
White	79.1	72.0	86.4
African-American	16.0	24.4	7.4
Other	4.9	3.7	6.2
Ethnicity, Hispanic/Latino*	3.7	7.3	---
Education, years	14.0 (1.8)	14.0 (2.0)	14.1 (1.6)
Employment status			
Full time	22.7	25.6	19.8
Part time	16.6	22.0	11.1
Homemaker	9.2	8.5	9.9
Not employed, retired	34.4	29.3	39.5

Variable	Total n = 163 <i>M (SD) or %</i>	REACH n = 82 <i>M (SD) or %</i>	Webinar n = 81 <i>M (SD) or %</i>
Not employed, not retired	11.0	7.3	14.8
Not employed, disabled	6.1	7.3	4.9
Household income, \$, Med (IQR)	4167 (4300)	4000 (3575)	4250 (5863)
Had military service	12.3	7.3	17.3
Caregiving duration, years	6.6 (3.8)	6.0 (3.8)	7.1 (3.7)
Veterans			
Male	85.3	82.9	87.7
Age, years	34.5 (6.4)	34.4 (6.9)	34.6 (5.9)
Marital status			
Married	6.8	8.5	4.9
Never married	54.0	53.7	54.3
Divorced/separated	38.7	37.8	39.5
Widowed	0.6	---	1.2
Live with parent	73.0	73.2	72.8
Have children	40.5	46.3	34.6
Employment status			
Full-time	4.3	3.7	4.9
Part-time	4.9	2.4	7.4
Not employed, retired	12.3	9.8	14.8
Not employed, not retired	1.8	1.2	2.5

Variable	Total n = 163 <i>M (SD) or %</i>	REACH n = 82 <i>M (SD) or %</i>	Webinar n = 81 <i>M (SD) or %</i>
Not employed, disabled	76.7	82.9	70.4
Military service, years	6.7 (5.0)	6.8 (5.4)	6.7 (4.6)
Military branch			
Army	58.3	56.1	60.5
Marines	14.7	13.4	16.0
Navy	14.1	18.3	9.9
Air Force	12.3	12.2	12.3
Coast Guard	0.6	---	1.2

Note: *statistically significant difference between arms, $p < 0.05$; IQR = interquartile range

Table 2

Mixed Model Analysis of Outcome Variables

Variable	Baseline	3 Months	6 Months	Group	Time	Group by Time
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	<i>p-value</i> ^a	<i>p-value</i> ^a	<i>p-value</i> ^a
Depression, PHQ-9 (0-27)				.222	<.001	.399
REACH	6.0 (4.3)	4.6 (3.5)	4.4 (3.4)			
Webinar	7.3 (5.8)	6.5 (5.4)	6.3 (4.9)			
Anxiety, GAD-7 (0-21)				.772	.008	.100
REACH	6.6 (4.7)	5.2 (3.7)	5.3 (4.3)			
Webinar	7.2 (4.6)	6.7 (5.2)	6.8 (5.1)			
Burden, ZBI (0-48)				.138	<.001	.576
REACH	15.7 (8.6)	13.0 (8.5)	13.4 (8.5)			
Webinar	17.9 (8.9)	16.0(8.7)	16.1 (9.7)			
Veteran behaviors (0-31)				.543	<.001	.910
REACH	13.8 (5.4)	12.3 (5.1)	11.9 (5.4)			

Webinar	14.4 (5.4)	12.9 (6.1)	12.6 (6.1)			
Bothersome behaviors (0-31)				.386	<.001	.001
REACH	12.3 (6.0)	8.6 (5.9)	6.5 (5.7)			
Webinar	13.0 (6.1)	9.9 (6.9)	10.1 (7.0)			

Note. $N = 163$ and $n = 82$ for REACH and 81 for Webinar.

Table 3.

Benefit Themes Reported by Participants

Theme	Examples
Resources	Talking to a live person with knowledge. I think of the program coach as a "catalyst," she got me to think about things in a certain way. Having a person to assist and to guide." Opened up areas, brought them to mind. Things I hadn't focused on. (Program Coach) was a pleasure, very empathetic. Helped me focus on addressing problems. She helped me prioritize. I think the webinars were really good. Some went into explanation of PTSD and TBI, the symptoms, signs, how to react to them. Anybody with a loved one with these issues. This should be handed out to them. Would've been so helpful in the beginning. The study...gives me the right techniques, ways, and strategies in dealing with a person like my son with special needs. I also learned more about his mental illness. I didn't understand his lack of decision-making. That just didn't make sense to me. Now I understand more...I've learned better ways to deal with my son and try to stay positive.
Self-reflection	It made me look at things from a different perspective...Made me get out of my old habits and think of things in a new way.

The questions asked made me realize I'm not the only one going through these things. He has asked us for a gun, and I keep saying No. Good to know I'm doing the right thing.

Until you asked these questions, I never thought about how my son affects my social life.

Being able to reflect and move forward...These questions make me realize I'm doing a good job.

Someone
cares/not alone

It's helpful to know that someone cares about me and my son.

I feel not alone. Makes me feel like myself. I'm not the only one going through this. What he (Veteran) does is normal.

Knowing I'm not alone, not the only one feeling this way really helped me.

Program coach was informative and caring, which is significant to an isolated parent.

Skills

Really liked the deep breathing and mindfulness. I'd never done that.

Really worked for me.

It helped both me and my daughter, especially our communication.

It helped me sharpen up on my listening skills.

Helps you come up with solutions or seek out solutions.

Self-efficacy

Put together a Caregiver plan to take care of myself.

Helped me to see the need to take care of myself.

It taught me to be a good Caregiver and be more supportive...I feel more confident as a Caregiver.

I am keen to correct what I thought I was doing well, and when studying and reading, this is far from reality.

Helping others My sincere desire is to help you do some research on Parents.

I'm really just hoping to help other Parents.

I initially enrolled in study to help the VA. Since I'm receiving services, I thought it would be good for me to help out.

A lot of people at Camp LeJeune need this information.

Stuff like this should be standard issue.

W81XH-17-C-0022 - Appendix 3

Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans

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Conflict of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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ABSTRACT

Background and Objectives. Parents who are frequently primary caregivers for unmarried and younger wounded, ill, and/or injured service members or veterans have not been extensively described. This paper examines baseline demographics, financial/career considerations, well-being, health status, and caregiving tasks for this less visible group of caregivers.

Research Design and Methods. Baseline data for parent caregivers (n=163) of wounded, ill, and/or injured veterans participating in a caregiver intervention randomized clinical trial were analyzed.

Results. Parents, on average, had been caregivers for 6.6 years and daily spent 7.7 hours providing care and 17.2 hours on duty. Parents were mainly mothers average age 60.2 years. Average burden score approached high, and average depression, anxiety, frustrations, and somatization scores were mild. The veterans had functional limitations; they could not fully carry out daily activities for an average of 16.7 days/month, and 9.2% were employed.

Caregiver burden was related to veteran TBI diagnosis, aggressive behavior toward others, and functional limitations. Caregivers of aggressive veterans also reported significantly more stress, depression, anxiety, frustrations, troubling behaviors, and bothersome behaviors, and less social support. Some parent caregivers worked full-time (22.7%); 85.3% had decreased personal spending, 84.0% dipped into personal savings, and 58.9% reduced retirement saving.

Discussion and Implications. Parent caregivers were taking care of functionally impaired adult children at financial and career cost to themselves. As these parents and their adult children age, providing care and resources may present greater challenges for them, for the military and veteran care systems they rely on for support, and for society.

KEYWORDS: military, older, parent-child relations, financing, long-term care

Introduction

Partners are primary caregivers for 62% of seriously wounded, ill, and/or injured service members/veterans, with mothers the primary caregivers for 19% and fathers for 3%. Friends (6%), siblings (4%), and other family members (3%) also serve as primary caregivers (Christensen, et al., 2009). For unmarried wounded, ill, and/or injured service members, the percent of parents who are primary caregivers is greater, with mothers being primary caregivers for 47% under 30 years and 33% for those over age 30, while fathers are primary caregivers for 4% of those under and 7% of those over age 30 (Christensen et al., 2009). The number of those needing care is not small. A study of 116,913 veterans receiving Department of Veterans Affairs (VA) chronic pain care who had or were suspected of having Traumatic Brain Injury (TBI) found that 53% were never married, and another 4% were currently not married (Seal, et al., 2017). For veterans receiving care in VA polytrauma rehabilitation centers, 53% of whom were unmarried, 62% were cared for by parents and 32% by spouses (Griffin et al., 2012).

About 31% of caregivers are also caring for someone else such as children and/or other adults, placing further burdens on finances and caregiver health (Christensen et al., 2009; Griffin et al., 2012). Most caregivers are not paid for their work, and about 60% have no help in providing care. When caregivers asked for help, about 32% report getting little if any help from others (Griffin et al., 2012).

Parents report feeling chained or tethered when providing care for a loved one with TBI (Kratz, Sander, Brickell, Lange, & Carlozzi, 2017). Caregivers often schedule appointments, assist with medication, provide transportation, provide personal care, pay bills, assist in household chores, and supervise childcare. Many caregivers become legal guardians due to veterans' cognitive limitations in handling budgeting (Allen & Resnik, 2007).

High intensity care is the primary reason for caregiver debt or asset depletion (Van Houtven et al., 2012). Many caregivers of veterans either reduce their work hours or quit altogether (Christensen et al., 2009; Ramchand et al., 2014). Besides cutting back hours or quitting work, caregivers may also experience financial stress by changing jobs, losing pension accruals or promotions, or from costs of care (Van Houtven et al., 2012).

Information is available on caregivers in general and information on how parent and spouse caregivers compare on outcomes. Some studies have found no difference in well-being or distress between parents and spouses who provide care to family members with TBI and/or Post Traumatic Stress Disorder (PTSD) (Delgado et al., 2018; Ennis et al., 2013). Others have shown that, compared to spouses, parents exhibit lower burden (Doser & Norup, 2016) and stress (Verhaeghe, Defloor, & Grypdonck, 2005) and better health (McPherson, Pentland, & McNaughton, 2000). However, most studies of caregivers dealing with polytrauma, TBI, and/or PTSD have not extensively characterized parent caregivers. This paper examines baseline demographics, financial and career considerations, well-being, health status, and caregiving tasks for a rarely studied and less visible group of caregivers – parent caregivers of their wounded, ill, and/or injured adult children who are veterans.

Design and Methods

Baseline data are presented for parent caregivers of wounded, ill, and/or injured adult children who could be service members or veterans. Caregivers were participating in a randomized clinical trial (RCT), April 2017 through March 2020, funded by US Army Medical Research and Development Command (USAMRDC) Military Operational Medicine Research Program. The study was conducted under VA Medical Center (VAMC) Memphis Institutional Review Board (IRB) and USAMRDC Human Research Protection Office oversight. The RCT is

testing two interventions to help parent caregivers: Resources for Enhancing All Caregivers' Health in the VA (REACH VA) individual session behavioral caregiver intervention and on-demand webinar education sessions.

Parent caregivers were recruited nationally through VA referrals, VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC), which provides training, health care services, and stipends to eligible caregivers, and military/veteran family websites and social media. Most participants contacted the study by telephone or email. Eligible parents were the primary/main caregiver for a post 9/11 service member or veteran with diagnosis of TBI, PTSD, or physical injury and at least one activities of daily living (ADL) or two or more instrumental ADLs (IADL) limitations; providing three or more hours of care per day for at least six months; and endorsing at least two caregiving stress behaviors, including feeling overwhelmed, angry/frustrated, or cut off from family/friends, often needing to cry, moderate/high levels of stress, and declining health. Exclusion criteria included current schizophrenia diagnosis or other mental illness or auditory impairment that would make telephone use difficult. After telephone screening, a consent form was mailed to the potential participant for an informed consent call, followed by telephone baseline data collection.

Data

All data are caregivers' self-reports at baseline. Data were collected by trained interviewers by telephone.

Caregiver and veteran demographics. Caregiver sex, age, marital status, race/ethnicity, education, military service, and caregiving duration were collected. For veterans, sex, age, marital status, living arrangement, children, employment, and military service and branch were collected.

Caregiver financial/career considerations. Finances included household income and estimate of monthly expenses due to caregiving. Percent of expenses as a function of monthly income was calculated separately for each caregiver. Financial strain was rated on a 5-point scale from 1 (not at all) to 5 (very much), and six specific financial actions that might be taken to pay for care, such as reduce retirement savings, were rated 0 (no) or 1 (yes) (Rainville, Skufca, & Mehegan, 2016). Career impacts were rated 0 (no) or 1 (yes) for eight items such as changed hours at work and retired early (National Alliance for Caregiving, 2004).

Caregiver well-being and health. The Patient Health Questionnaire (PHQ-9) assessed depression (Kroenke, Spitzer, & Williams, 2001). PHQ-9 has nine items based on DSM-IV depression diagnostic criteria scored from 0 (not at all) to 3 (nearly every day). Cut points for depression are <5 (minimal), <10 (mild), <15 (moderate), <20 (moderately severe), or ≥ 20 (high/severe).

The Generalized Anxiety Disorder (GAD-7) scale assessed anxiety. This 7-item symptom checklist demonstrates good performance in detecting generalized anxiety disorder, panic disorder, social anxiety disorder, and PTSD (Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007; Spitzer, Kroenke, Williams, & Löwe, 2006). Scoring for each item ranges from 0 (not at all) to 3 (nearly every day) for a summed score of 0 to 21, higher scores indicating more anxiety. Cut points of 5, 10, and 15 represent mild, moderate, and severe levels of anxiety (Spitzer et al., 2006).

Caregiver burden was assessed using the 12-item Zarit Burden Interview (ZBI) short version (Bédard et al., 2001; Zarit, Reever, & Bach-Peterson, 1980). Items are scored 0 (never) to 4 (nearly always), with higher scores indicating greater burden. A summed score of ≥ 17 indicates severe/high burden (Stagg & Lerner, 2015).

Two Frustrations of Caregiving Scale items assessed caregiver frustrations (i.e., feel like yelling at or hitting patient) (Burgio et al., 2009). These are scored from 0 (never) to 2 (often) with higher scores indicating more frustration. Caregivers were asked to rate general stress using a 10-point scale, with 10 representing extremely stressed. Expanding on this rating and helping identify intervention targets was the frequency (often, sometimes, never) of the five stress symptoms from the recruitment screen, such as feeling overwhelmed or crying during the past month. Any frequency of occurrence was counted as present. Caregiver Vigilance Scale (Mahoney et al., 2003) measures of vigilance included time spent providing care and overall time spent “on duty” per day.

Ten social support items assessed support in the past month, including type and satisfaction with received support (help with tasks, emotional support, information and guidance) (Krause, 1995; Krause, 1997; Krause & Markides, 1990), and negative interactions (demanding, criticizing, prying, taking advantage) (Krause, 1995). The three domains use a scale of 0 (never, not at all) to 3 (very often, very). Total social support score, 0 through 30, is a sum of all ten items, with higher scores indicating more support.

Caregiver health was scored from poor (0) to excellent (4), using one Medical Outcomes Study Short-Form 36 (Ware et al., 1995). Somatic symptoms and severity were measured by the Patient Health Questionnaire (PHQ-15) (Kroenke, Spitzer, & Williams, 2002). Thirteen of the 15 items are rated on a 3-point scale ranging from 0 (not bothered at all) to 2 (bothered a lot). Two items, sleep problems and tiredness, are from the depression scale (PHQ-9) and recoded to match the 3-point scale. Scores of ≥ 5 , ≥ 10 , and ≥ 15 represent mild, moderate and severe levels of somatization (Kocalevent, Hinz, & Brahler, 2013). Self-care (Belle et al., 2006) included 14 items, such as keeping health care appointments, being able to rest when ill, receiving counseling

or support services, physical activity, and sleep, scored 0 (no) or 1 (yes) and summed, with higher scores indicating more self-care

Veteran function. Caregivers reported veteran diagnoses. Veteran's functional ability was assessed using 6-item Katz ADL Scale (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) and 8-item Lawton and Brody IADL Scale (Lawton & Brody, 1969). Each item is scored 0 (no help needed) or 1 (help needed). ADL and IADL are summed separately, with higher scores indicating more impairment. Also for the veteran, the caregiver answered the 39-item World Health Organization Disability Assessment Schedule 2.0 (WHODAS) (Üstün, 2010). Three WHODAS questions ask how many days/month the veteran cut back on or was unable to carry out daily activities and how many days/month symptoms were present. The remaining 36 questions assess difficulty functioning in six domains: cognition, mobility, self-care, getting along, life activities, and participation. Ratings range from 0 (none) to 4 (extreme/cannot do). Due to the small number of responses, four work and school participation questions were not included in the summed score. Thus, 32 summed items gave a score from 0 to 128. A score of 39.9 can identify individuals with functional impairment with maximal sensitivity and specificity among veterans with PTSD (Marx et al., 2015).

Veteran behaviors were assessed in three ways. In intervention development for the RCT, national polytrauma subject matter experts, including clinicians, researchers, and caregivers, identified relevant safety risks and potentially troubling behaviors. Six safety risks, such as concern over access to a gun or harming self or others were assessed as present or absent. Thirty-one potentially troubling behaviors were rated as 0 (absent) or 1 (present) during the past month. For each behavior present, the caregiver was asked about bother or concern. The 31 behaviors include physical and functional difficulties (e.g., mobility, problems with wounds,

breathing, vision, or sleeping), cognitive/affective concerns (e.g., difficulty concentrating, sadness, loss of interest), and behavioral concerns (e.g., relationship difficulty, flashbacks, unpredictable, reckless, self-destructive behavior). Both presence of troubling behaviors and behaviors that are bothersome/concerning are summed to produce scales with scores from 0 to 31, with higher scores signifying more behaviors and more bothersome behaviors.

Analysis

Descriptive statistics were used to characterize participants' baseline data. Statistical comparisons were independent samples t-tests. Measures of associations between variables are Pearson's r , point-biserial coefficients, or phi coefficients, as appropriate. All measures of central tendency reported are means (SD), except where noted. P values $\leq .05$ were considered statistically significant. Effect sizes were estimated as mean difference relative to estimated population standard deviation. Small effect sizes begin at $d = 0.2$, with medium at 0.5 and large at 0.8 (Cohen, 1988).

Results

Caregiver and Veteran Demographics

There were 162 parent caregivers of a veteran adult child who was wounded, ill, and/or injured plus one caregiver of an active duty service member who was transitioning (**Table 1**). Parent caregivers were mostly mothers (89.6%) with average age of 60.2 years, and 57.1% were married. Average length of caregiving was 6.6 years. About 90% were participating in VA's PCAFC.

Veterans were mostly male (85.3%) with average age of 34.5 years (**Table 1**). Few (9.2%) were employed, and 73% lived with their parent. Most (54.0%) were never married.

Caregiver Financial/Career Considerations

Income distributions were skewed; calculations showed that eight caregivers were spending 100% or more of reported income on care expenses. Therefore, medians and interquartile ranges were calculated (**Table 2**). Median monthly household income was \$4,167; median care expenses were \$350 per month; median care expenses as a percent of monthly income were 8.3%. To make ends meet, caregivers reported cutting personal spending (85.3%), dipping into personal savings (84.0%), or reducing retirement saving (58.9%). Caregiving had career impacts for many caregivers with 39.3% employed, and 22.7% employed full time (**Table 2**).

Caregiver Well-Being and Health

Mean scores for depression (6.6) and anxiety (6.9) were consistent with mild symptom scores. However, 23.3% reported moderate or greater depression, and 30.1% reported moderate or greater anxiety (**Table 3**). Mean score for burden (16.8) approached the severe cutpoint of 17; 46.0% reported greater than severe burden. Because fewer caregivers were married than is the case for other chronic conditions such as dementia, marital status and burden relationship was examined. There was a correlation between caregiver marital status and burden ($r = 0.168, p = .032$), with married caregivers reporting higher burden. Because caregiver average age was higher than expected, relationship between caregiver age and burden and burden and veteran age were examined. There was no correlation between caregiver age and burden, there was between veteran age and caregiver burden ($r = -0.178, p = .023$), with caregivers of younger veterans reporting more burden.

Caregivers reported spending, on average, 7.7 hours per day providing care and 17.2 hours per day being on duty (**Table 3**). Caregivers reported mean moderate stress of 5.2 and endorsed stress symptoms. Almost all reported feeling overwhelmed (96.3%); most also

reported feeling frustrated (87.7%). Parent caregivers reported receiving very little social support but were moderately satisfied with support the quality and rarely reported negative interactions.

On average, caregivers reported good health and mild somatic symptoms. However, 38.7% met the moderate somatization cutpoint. Although caregivers reported, on average, practicing half (8.6) of the sixteen self-care items (**Table 3**), 71.8% reported poor sleep and 79.1% reported cutting back on physical activity (data not shown in tables).

Veteran Function

As reported by caregivers, most veterans (63.2%) had two to four diagnoses, 12.3% had one diagnosis, and 24.5% had more than five. Three commonly reported diagnoses were PTSD, TBI, and physical injuries (e.g., back, knee, or shoulder musculoskeletal injury, paraplegia, quadriplegia, amputee, wheelchair bound, spinal cord injury, walking difficulty), followed by mood disorders (e.g., depression, anxiety, bipolar), and psychoses (e.g., schizophrenia, schizoaffective) (**Table 4**). Caregivers reported 42.3% had both PTSD and TBI, and five caregivers did not report PTSD or TBI for their veterans.

Caregivers helped with about two ADLs and more than six IADLs (**Table 4**). The ADLs caregivers assisted most with were grooming and dressing. IADLs that more than 75% of caregivers reported helping with were cooking, housework, managing medications, doing laundry, managing finances, and transportation (data not shown in tables).

Parent caregivers reported functional impairment levels between mild and moderate for WHODAS cognition, mobility, self-care, and getting along domains, and levels between moderate and severe for life activities and participation domains. Total WHODAS score had a correlation with caregiver burden ($r = 0.361, p < .001$). In the past month, symptoms were

present a mean of 28.3 days, and parent caregivers reported an average of 9.5 days the veteran was unable to carry out usual activities and 7.2 days the veteran cut back on usual activities. There was no correlation between caregiver burden and number of veteran impairment days.

On average, caregivers reported 14.1 of 31 potentially troubling behaviors occurred in the past month. Two-thirds or more (>66%) of caregivers reported the following behaviors occurred: sleep disturbance, difficulty concentrating, confusion and decision-making difficulty, sadness/depression, aggression, avoiding/isolating, losing interest in activities, or being hypervigilant (data not shown in tables). Caregivers reported, on average, 12.7 of these behaviors were bothersome or concerning. *Phi* coefficients between individual behaviors and corresponding bother were strong (greater than .6) or very strong (greater than .8) (Rea & Parker, 1992). Behaviors that were most likely to be bothersome, with over 97% of caregivers who reported the behavior reporting concern were: being resistant to getting help, reckless or self-destructive behavior, relationship problems, excessive anxiety or worry, impulsive spending, and unpredictable or inconsistent behavior.

Parents reported an average of 1.1 safety risks with aggression/violence toward others (30.7% and substance abuse (25.2%) most commonly reported. Because violence and anger (Delgado et al., 2018; Galovski & Lyons, 2004; Ray & Vanstone, 2009) and perceived threat (Manguno-Mire et al., 2007) are associated with decreased caregiver well-being, caregivers who did or did not report that their loved one was aggressive or violent toward others were compared. Although they did not report more time providing care or being on duty, caregivers with a loved one who was aggressive or violent reported significantly more stress, depression, anxiety, burden, frustrations, troubling behaviors, and bothersome behaviors, and less social support (**Table 5**). Statistically significant outcomes had corresponding effect sizes ranging from small

to large. PTSD diagnosis had an association with aggression ($\phi = .16, p = .040$); no other diagnosis had significant association with aggression.

Discussion and Implications

Most studies of caregivers dealing with polytrauma, TBI, and/or PTSD that have included parents caregivers have not extensively characterized them. This paper examined parent caregivers of wounded, ill, and/or injured veteran adult children. Caregivers were participating in an RCT focusing on interventions to assist parent caregivers. Two areas of interest were to describe the parent caregivers and to explore how parents compared to other types of caregivers for wounded, ill, and/or injured veterans.

Parent caregivers provided an average of 54 hours/week of care and had been providing care, on average, for almost seven years; most reported little social support. The veterans were functionally limited, particularly in life activities and social participation. This was evidenced in small numbers who were working full or part time and in the 16.7 days per month, on average, that veterans were not able to fully carry out daily activities. Parent caregivers reported average burden score of 16.8, approaching high burden, which is associated with adverse psychological caregiver consequences (Dekel, Solomon, & Bleich, 2007), and their average scores for depression, anxiety, and somatic symptoms were in the mild range. Caregiver burden was related to veteran TBI diagnosis, veteran aggressive behavior toward others, and veteran functional limitations. Parent caregivers of veterans with a PTSD diagnosis spent fewer hours providing care and on duty per day but reported more veteran behaviors and bothersome behaviors.

These parent caregivers are similar to and different from other groups of caregivers providing care for similar conditions. Number of hours of care provided per week (53.9) was

like that of caregivers of veterans nationally, 22% of whom report providing 41 to 80 hours per week and 21% report more than 80 hours/week. Almost a quarter of caregivers of veterans with polytrauma (23%) (Griffin et al., 2012) and of wounded, ill, and/or injured service members (22%) (Christensen, et al., 2009), and 32% of parent caregivers for their veteran adult children provide more than 40 hours of care per week (National Alliance for Caregiving, 2010). For caregivers of adults nationally, caregivers spend on average 21 hours per week providing care (National Alliance for Caregiving, 2004).

The parent caregivers had been providing care for 6.6 years, and nationally 56% of caregivers of veterans have been caregivers for more than five years (NAC, 2010). Diagnosis prevalence reported by the parent caregivers differ from those reported nationally by caregivers of veterans, including mental illness (39% vs. 70%), PTSD (80% vs. 60%), and TBI (59% vs. 29%) (NAC, 2010). For these parent caregivers and veterans' caregivers nationally, grooming/dressing is the most common ADL assistance provided. Assistance with cooking, housework, managing medications, doing laundry, managing finances, and transportation are all reported by both groups.

Demographically, these parent caregivers resemble caregivers of adults nationally in marital status (56% vs. 62% married) (NAC, 2004). Although 59% of caregivers of adults are employed (NAC, 2004), the percent of these parent caregivers who are employed full time (22.7%) is like caregivers of veterans nationally (27%) (NAC, 2010). While 49.1% of parent caregivers gave up working entirely, 47% of caregivers of veterans nationally (NAC, 2010) and 43% of caregivers of wounded, ill, and/or injured service members (Christensen et al., 2009) did so. For caregivers of adults nationally, which includes all levels of caregiving, far fewer (9%) have quit work (NAC, 2004).

Average yearly income for this sample was \$50,004. In 2010, 49% of caregivers of veterans nationally reported income less than \$50,000 and 21% had income between \$50,000 and \$74,999 (NAC, 2010). Nationally, family caregivers spend \$6,954, about 20% of their income, on caregiving expenses (Rainville et al., 2016). This percent is larger than the 8.3% reported in this study. However, compared to caregivers nationally (Rainville et al., 2016), more parent caregivers had cut back on their spending (45% vs. 85%), dipped into their savings (30% vs. 84%), or reduced retirement savings (16% vs. 59%).

Limitations

One study limitation is that all data are caregiver self-report, including veteran diagnoses. Also, while not strictly a limitation, most parents reported multiple diagnoses for the veteran. Therefore, conclusions drawn based on diagnosis are not based on verified clinical data nor can they be attributed to any one condition. Another study limitation is a potential threat to generalizability. More than 90% of parent caregivers were participating in VA's PCAFC, which means they were taking care of a veteran who has been clinically determined to need a full-time caregiver. Consequently, the parent caregivers resemble this group in burden and full-time employment but had been providing care longer (Smith et al., 2019). Other veterans or service members receiving care from their parents may not be as severely wounded ill or injured, and their caregivers may differ. The parent caregivers had to meet study eligibility criteria of endorsing two caregiving stress behaviors. This may have resulted in a more stressed sample than others providing the same type of care.

Implications

These parent caregivers of their wounded, ill, and/or injured adult children veterans report high perceived burden, which indicates a need for support and attention from military,

veteran, and community systems they interact with, as active duty service members transition to community living and VA care. This transition is not always smooth because there can be issues of pay or care lapses (Christensen et al., 2009).

Parents' current needs and need for support are like those of other caregivers of veterans. However, because they are parent caregivers, their future course of caregiving is unclear. Consequences of military service linger – these parents had been providing care, on average, for seven years. Four years after a polytraumatic injury, 70% of caregivers of veterans were still providing assistance (Griffin et al., 2012). Almost half (43%) of seriously wounded, ill, and/or injured service members report that they need a long-term caregiver (Christensen et al., 2009).

Questions arise for parent caregivers about what will happen to them and their adult children as both age (Tanielian et al., 2013). As wounded, ill, and/or injured veterans age, one potential challenge is increased risk of dementia. TBI, PTSD, and/or depression were common in this sample of veterans and are all risk factors for dementia (Barnes et al., 2018, 2014). In addition, physical caregiving challenges will increase, as parents and their children age and face additional health problems and physical challenges. Physically and/or cognitively frail parents may also need care – which these adult children may not be able to provide.

As both parent caregivers and veterans age their care expenses are likely to increase. These parents were in what should be their prime career/work years, earning at their highest level. Instead, less than a quarter were working full-time, and less than 10% of veterans were working at all. Because both parents and veterans have decreased job market participation, the resources available to provide care for both will be less. Caregiving for parents in earlier life raises women's poverty risks in later life, as caregivers experience missed opportunities and lost earnings and as they tap into savings to provide care (Wakabayashi & Donato, 2006). These

same financial and career dynamics are likely to be true for parent caregivers for military and veteran wounded, ill, and/or injured adult children.

Additional research is needed to answer questions about the trajectory of parent caregivers and their adult children veterans as they age. More in-depth analysis of finances, career impacts, and resources would help determine what level of future support may be needed. Because these parents reported a small amount of support, family systems analysis would be of interest, for example, in determining the role of the veteran's siblings in providing care. Determination of types of caregiver interventions most suitable for parents would be of benefit.

Nationally, support for caregivers is becoming more visible. With passage of the 2018 Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act establishing the Family Caregiving Advisory Council and a national Family Caregiver Strategy, policies and initiatives to support family caregivers are being discussed at state and federal levels. DoD is exploring TBI and dementia through the Peer Reviewed Alzheimer's Research Program that aims to reduce the burden on affected military and veteran individuals and caregivers. VA is expanding its programs of caregiver support to include pre- and post-9/11 veterans and their caregivers. These initiatives should help parent caregivers. However, these initiatives are largely designed to support caregivers who are in place. For parent caregivers of wounded, ill, and/or injured veteran adult children, as needs change and finances are compromised, care for both the parents and veterans may become the responsibility of siblings, the veteran's children, or extended family members. However, if family systems are not in place, care for those injured in service to their country may increasingly become the responsibility of the broader military, veteran, and general community.

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Table 1.

Caregiver and Veteran Demographics (n = 163)

Variable	Caregivers	Veterans
	<i>M (SD)</i> or %	<i>M (SD)</i> or %
Female	89.6	14.7
Age, years	60.2 (6.8)	34.5 (6.4)
Marital status, married	57.1	6.7
Marital status, never married	7.4	54.0
Marital status, divorced/separated	25.2	38.6
Race, White	79.1	
Race, African-American	16.0	
Ethnicity, Hispanic/Latino	3.7	
Education, years (range 4-17)	14.0 (1.8)	
Had military service	12.3	
Caregiving duration, years (range <1-16)	6.6 (3.8)	
Live with parent		73.0
Have children		40.5
Employed, full-time		4.3
Employed, part-time		4.9
Military service, years (range <1-36)	6.7 (5.0)	
Military branch, Army	58.3	
Military branch, Marines	14.7	
Military branch, Navy	14.1	
Military branch, Air Force	12.3	

Table 2.

Caregiver Financial/Career (n = 163)

Variable	<i>M (SD) or %</i>
Household income, monthly, US \$, median (IQR)*	4,167 (4300)
Care expenses, monthly, US \$, median (IQR)	350 (600)
Care expenses, % of income, US \$, median (IQR)	8.3 (17.7)
Cut back on personal spending	85.3
Dip into personal savings	84.0
Reduced retirement saving	58.9
Take out loan	46.0
Dip into retirement savings	30.1
Cut back on health spending	29.4
Financial strain (0-4)	2.9 (1.5)
Employed, full-time	22.7
Employed, part-time	16.6
Go in late, leave early	55.8
Give up working entirely	49.1
Take leave of absence	37.4
Lose job benefits	32.5
Go from full to part time	29.4
Take early retirement	27.0
Turn down a promotion	15.3

*Interquartile range

Table 3.

Caregiver Well-Being and Health (n = 163)

Variable	<i>M (SD)</i> or %
Depression, PHQ-9 (0-27)	6.6 (5.2)
Anxiety, GAD-7 (0-21)	6.9 (4.7)
Burden, ZBI (0-48)	16.8 (8.8)
Caregiving frustrations (0-4)	0.8 (0.8)
Caregiver time providing care/day, hours	7.7 (4.5)
Caregiver time on duty/day, hours	17.2 (7.8)
General stress (1-10)	5.2 (2.3)
Overwhelmed	96.3
Frustrated	87.7
Cry	77.3
Lonely	65.0
Feel cut off	54.0
Total social support (0-30)	16.0 (5.8)
Received support (0-9)	2.8 (2.1)
Satisfaction with support (0-9)	4.2 (2.9)
Negative support (0-12)	3.0 (2.7)
General health (0-4)	2.1 (0.8)
Symptoms and severity (0-30)	8.3 (4.4)
Self-care (0-14)	8.6 (2.4)

Table 4.

Veteran Function (n = 163)

Variable	M (SD) or %
Diagnoses	
PTSD	80.4
TBI	58.9
Physical injuries	56.4
Mood disorder	22.7
Psychoses	13.5
ADL (0-6)	1.7 (2.0)
IADL (0-8)	6.5 (1.3)
WHODAS (0-128) ^a	61.2 (22.9)
Cognition (0-24)	11.3 (5.3)
Mobility (0-20)	7.7 (6.3)
Self-care (0-16)	5.5 (4.6)
Getting along (0-20)	9.3 (4.8)
Life activities (0-16) ^a	10.7 (4.4)
Participation (0-32)	16.9 (6.2)
Days unable to carry out activities	9.5 (10.3)
Days cut back on activities	7.2 (6.9)
Days symptoms present	28.3 (5.2)
Troubling behaviors (0-31)	14.1 (5.4)
Bothersome behaviors to caregiver (0-31)	12.7 (6.0)
Safety risks (0-6)	1.1 (1.3)

^a Calculated without four work/school questions because sample had so few working or in school

Table 5

Comparison between Caregivers of Veterans with and without Aggression

Variable	Aggression		No Aggression		p^a	d
	(n = 50)		(n = 113)			
	M	SD	M	SD		
Depression, PHQ-9 (0-27)	8.3	5.8	5.9	4.7	.007	0.47
Anxiety, GAD-7 (0-21)	9.0	4.8	6.0	4.3	<.001	0.67
Burden, ZBI (0-48)	19.9	9.2	15.4	8.3	.002	0.53
Caregiving frustrations (0-4)	1.2	0.8	0.6	0.7	<.001	0.80
Time providing care (hours/day)	7.1	4.4	7.9	4.5	.325	0.20
Time on duty (hours/day)	18.3	7.5	16.8	8.0	.240	0.17
General stress (0-10)	5.9	2.2	4.9	2.2	.006	0.48
Total social support (0-30)	14.5	5.2	16.7	5.9	.025	0.39
Somatization, PHQ-15 (0-30)	9.2	4.6	7.8	4.3	.063	0.32
Behaviors (0-31)	16.4	4.2	13.1	5.6	<.001	0.64
Bothersome behaviors (0-31)	15.6	4.3	11.4	6.3	<.001	0.72

^a Statistical comparisons were independent samples t-tests.

Appendix 4

W81XH-17-C-0022 - Dissemination Activities

All materials are available upon request. linda.nichols@va.gov

Presentations

Nichols, L.O., Martindale-Adams, J. Supporting Parents of Injured Service Members. Army Military Operational Medicine Research Program (MOMRP) Meeting, May 3, 2018.

Martindale-Adams, J, Zuber J, Graney M, Burns R, Nichols LO. Supporting Parents of Injured Service Members. Poster Presentation, Military Health System Research Symposium, Kissimmee, FL, August 20-24, 2018.

Nichols, L.O., Martindale-Adams, J. Supporting Parents of Injured Service Members. Military Operational Medicine Research Program (MOMRP), July 30, 2019

Martindale-Adams J, Zuber J, Graney MJ, Burns R, & Nichols LO. Supporting Caregivers of Veterans with Post Traumatic Stress Disorder. Presentation, Military Health System Research Symposium (MHSRS), Orlando/Kissimmee, FL, August 19-22, 2019.

Martindale-Adams, J, Zuber J, Graney M, Burns R, Nichols LO. Supporting Parent Caregivers of Wounded, Ill, and/or Injured Veterans. Abstract accepted for Military Health System Research Symposium 2020

Manuscripts

Martindale-Adams, J, Zuber J, Graney M, Burns R, Nichols LO. Caring Again: Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans. Submitted to *The Gerontologist*, June 2020. Appendix 3.

Martindale-Adams, J, Zuber J, Graney M, Burns R, Nichols LO. Support for Parent Caregivers of Wounded, Ill, and/or Injured Adult Children Veterans. Manuscript in progress. Appendix 2.

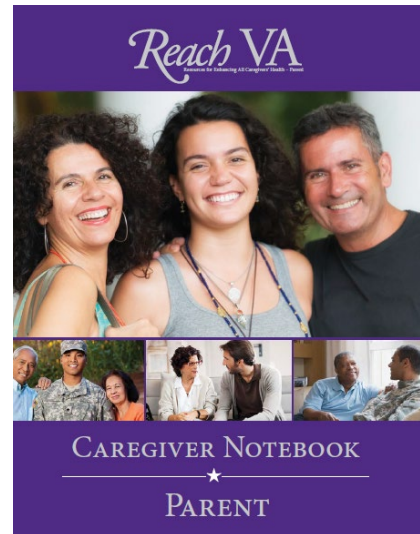
Publicity

VA Research Currents. Trial comparing programs for parent caregivers of Vets, service members. By Mike Richman, VA Research Communications. August 29, 2018.

Intervention Products

REACH VA Parent Risk Assessment – used to assess risks in caregiver education, safety, emotional and physical well-being, and social support, and care recipient behavioral management

REACH VA Parent Caregiver Notebook – Caregiver information and workbook with 17 chapters on care recipient behavioral management and 17 chapters on caregiver stress and coping, 336 pages, worksheets for each chapter. Will be used in REACH VA intervention throughout the VA healthcare system. Chapters include:



Using Your Caregiver Notebook	SECTION 2: CAREGIVING
SECTION 1: BEHAVIORAL ISSUES	Addressing Problems
An Overview for Post 9/11 Parents	Asking for Help
Blast Related Injuries	Challenging Emotions
Pain	Communicating with Health Care Providers
Post Traumatic Stress Disorder	Communicating With Your Loved One
Spinal Cord Injury/Disorders	Depression
Traumatic Brain Injury	Family Roles
Accessibility and Equipment	Financial and Legal Concerns
Depression	Finding Resources
Driving	Healthy Lifestyle
Emergency Preparations	Holidays
Hygiene	Making New Friends
Lifting and Moving	Mood Management
Nutrition	Navigating the System
Safety Concerns	Organizing Your Caregiving Life
Sleeping	Stress Management
Socializing	Taking Care of You
Substance Abuse	
	REFERENCES
RED FLAGS	
Safety Plan	
Abuse	
Firearms	
Suicide Prevention: Know the Warning Signs	
Understanding and Dealing with Anger	

REACH VA Parent Caregiver Videos

These videos are located on the Caregiver Center/REACH VA YouTube channel. While targeted to parents, these are relevant for any caregiver taking care of a service member or veteran with polytrauma, TBI, and/or PTSD.

Introduction and Post 9/11 Injuries – common injuries; VHA health care team, accessibility and mobility; hygiene; safety concerns; and technology assistance

<https://www.youtube.com/watch?v=uL1NZE5cHN8>

Challenging Emotions and Behaviors for the Veteran – emotional issues; communication; sleep; pain, substance abuse; social avoidance; hygiene; overspending; depression

<https://www.youtube.com/watch?v=Pa4QRZvcy9Y>

Caregiver Physical Health – healthy lifestyle; exercise; sleep; appointments; nutrition; finances and legal; benefits and resources; navigating the system; communicating with health care providers; family roles; interdependence; taking care of you; personal goals

https://www.youtube.com/watch?v=xBVnJ5uml_M

Caregiver Emotional Health – Stages of loss and grief; coping; communication; patience; feelings; goals; support groups; feeling unappreciated; miscommunication; depression

<https://www.youtube.com/watch?v=xdNlf-ZHARw>

Caregiver Social Support – barriers to support; making friends; asking for help; online resources; self-reliance; de-stressing; self-talk; significant other relationships; socializing

<https://www.youtube.com/watch?v=CgOM-TNDIEs>

Red Flags and Review – guide for unsafe or dangerous behaviors; safety plan for red flag behaviors; firearms; suicide prevention; dealing with anger; domestic violence; abuse

https://www.youtube.com/watch?v=8_9nRH390B4