

THE CAREGIVING EXPERIENCE OF WIVES OF VETERANS WITH
COMBAT-RELATED TRAUMA AND DEMENTIA

A Thesis

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Abstract

Purpose. The purpose of this study was to describe the caregiving experiences of wives of combat-exposed veterans who now have dementia. There is growing investigation of intersections between combat-related trauma and dementia, but a paucity of research exists on adaptations that caregivers make between the two conditions. *Methods.* Semi-structured interviews were conducted with four wives of combat veterans with dementia. Data were transcribed and analyzed using qualitative description and content analysis. *Findings.* Themes clustered into two main categories: 1.) *relationship*; 2.) *caregiver experience*. Veterans' avoidance of conversation regarding combat experience, which had emotional impact on both the dyad and the wives, was common across participants. No clear demarcation between combat-related trauma and dementia was found. There were adaptations made to accommodate the avoidance of emotionally charged topics. Occupational therapists should be aware of the special needs and the caregiving experience of this particular cohort.

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The Caregiving Experience of Wives of Veterans with Combat-Related Trauma and Dementia

Background

Many soldiers returning from combat in World War II experienced what have been generically described as “post-combat disorders.” Specific names include “shell shock” in the First World War and “war neurosis” in the Second World War. Posttraumatic stress disorder (PTSD) was first officially recognized in 1980 as a diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM III, American Psychiatric Association, 1980). According to the current edition, symptoms include sleep disturbance, angry outbursts, startle response, and avoidance of thoughts, feelings, or conversations that the individual associates with the trauma (American Psychiatric Association, 2000). Jones et al. (2003) compared specific PTSD symptoms in veterans of the First and Second World Wars with those in the Vietnam War, and found the incidence to be higher in the Vietnam cohort. PTSD remained unrecognized until several years after the end of the Vietnam conflict, and symptoms may not have been easily observed (Bonwick & Morris, 1996). Other studies suggest that older veterans had PTSD symptoms that persisted for or were recognized up to 75 years after their service in the First and Second World Wars (Archibald & Tuddenham, 1965; Hamilton & Workman, 1998; Port, Engrail, & Frazier, 2001). These findings suggest that although soldiers have experienced combat-related trauma differently throughout history, the consequences of combat exposure are significant for

many, and may be unlabelled or masked under different names (Jones, 2006).

Veterans returning from war, particularly those who had combat exposure, experienced many intrapersonal and interpersonal difficulties, including in their marital relationships (Evans, McHugh, Hopwood, & Watt, 2003). When considering marital dynamics, the psychological effects of living with a combat veteran with PTSD have been most widely discussed in regards to Vietnam-era couples (Calhoun, Beckham, & Bosworth, 2002; Dekel, Goldblatt, Keidar, Solomon, & Polliack, 2005; Lyons, 1999). Studies on partners of veterans with PTSD indicate that wives must make a psychological adjustment in order to cope with their partners' illnesses (Calhoun et al., 2002) and that the couples experience a general sense of distressed relationship (Evans et al., 2003). Lyons (1999) outlined three phases of the relationship between veteran and partner: an early phase, called *adjustment*, a middle phase, called *enmeshment*, and a later phase, called *resolution/healing*. The wives in her study identified with their husbands' experiences, such that the illness became a central focus of their relationship and family structure. Less research has been conducted on the relationships between combat veterans and their wives in wars prior to Vietnam. This may be due in part to the lack of consistency in clinical diagnosis of PTSD in elderly veterans. Falk, Hersen, & Van Hasselt (1994) suggest that the psychological issues experienced by these veterans may have been

mistaken for somatic symptoms, or that there was less help-seeking for mental health issues due to associated social stigma.

Studies have suggested higher dementia risk in patients with PTSD or increase of PTSD symptoms with onset of dementia (Johnston, 2000; Mittal, Torres, Abashidze, & Jimerson, 2001; Yaffe et al., 2010). I have found no research that specifically addresses the intersections of PTSD and dementia in terms of caring for a partner with both of these conditions. Research on the relationship between PTSD and dementia is growing. As knowledge of how or whether these two conditions are interrelated expands, it becomes a priority to understand the experience of wives who care for their husbands through both conditions.

The majority of caregivers for older adults are women, and caregiving has been mainly associated with the notions of burden and stress (Barusch & Spaid, 1989; Family Caregiver Alliance, 2011; Fitting, Rabins, Lucas, & Eastham, 1986). Until fairly recently, the positive effects of caregiving have been overlooked (Farran, Miller, Kaufman, Donner, & Fogg, 1999). Previously, the focus of caregiver research was on creating interventions to increase the caregiver's sense of well being, but Kramer (1997) argued that research should focus on both positive and negative outcomes in order to gain perspective on caregiver adaptation. Gaugler, Kane, and Newcomer (2007) used the concept of resilience to describe the way caregivers manage the potential burden and stress of their roles. Resilience may be important in integrating both positive and negative aspects of caregiving, as it is determined

by individual and contextual factors.

Increased understanding of the intersections of combat-related trauma and dementia is essential to provide for the unique needs of wives who are caring for veterans with both these conditions. The current study describes the experiences of four wives of veterans who had combat-related trauma and currently suffer from symptoms of dementia. It considers the necessary adaptations that are made in the transition to caring for a husband with dementia, and will describe the experiences of a cohort that has been previously overlooked.

Methods

This multiple-case study design allows for in-depth construct development of the lived experiences of wives caring for combat veterans with dementia. This study describes four wives' adaptations to the demands of their evolving caregiving roles. Interview transcripts and field notes comprised the data used in the qualitative descriptive analysis. The small, exploratory nature of this study allowed for an in-depth focus on a few women in order to help develop the construct of a little-understood experience.

Participants

The main inclusion criteria for this study were: 1) wives of veterans who had combat (WW II, Korea, or Vietnam) exposure, and 2) wives who considered themselves primary caregivers of partners with dementia.

Prior to recruiting participants, the Tufts University Institutional Review Board approved the study (Appendix A). Participants were recruited using a

purposive sampling method through word-of-mouth and direct calls to local elder day programs serving individuals with memory loss. Five potential participants were screened using the inclusion criteria. One of these women was willing but not eligible to participate as her husband was a veteran who had never seen combat. The four remaining were determined eligible and agreed to participate in the study. Each participant provided written informed consent before the start of each interview.

When identifying potential participants, it was determined to be impractical to anticipate a clinical diagnosis of PTSD for these veterans. Many of the symptoms of PTSD in this cohort remain unrecognized. As such, a general telephone pre-screening (Appendix D) was used to identify potential symptoms in the veterans such as hypervigilance, sleep disturbance, angry outbursts, or avoidance behaviors (American Psychiatric Association, 2000). Our primary criterion for trauma history was combat exposure.

Participant characteristics are shown in Table 1. Participant ages ranged from 64 to 83 with a median age of 74. All participants were white, and all of the involved veterans were enrolled in adult day care programs, two to five days per week. Only one of the veterans had a clinical diagnosis of PTSD and all had a diagnosis of neurodegenerative dementia. Wives' names have been changed to protect anonymity.

Marie and her husband raised four children together. After retiring from the Marine Corps, her husband took a second career as a police officer.

When the children began to move out of their house, Marie took a position as a legal secretary, and kept her job for nearly 30 years. Rose met her husband through translating letters for her landlady (her future husband's aunt) during the war. The couple met shortly after the war ended and were married when Rose was 18. As she stated, "that's your whole life." Beverly met her future husband in high school, before he was drafted into service in Vietnam. Within six months of his return, he was admitted to the hospital with viral encephalitis. Symptoms of multiple sclerosis began surfacing shortly thereafter, eventually resulting in a diagnosis of multiple sclerosis with onset of encephalitis. Beverly has had the longest term of caregiving for her husband – nearly 40 years, running the entire course of their marriage. Catherine is in her second marriage; both husbands were military officers. Her first marriage as well as a portion of her second revolved around the military life, relocating her family to follow her husbands' careers. For the purposes of this interview we focused on her current marriage.

Table 1. Participant demographic information.

Participant	Age	Ethnicity	Husband's comorbidities	Combat theater	Years married	Wife's former employment
Marie	64	White	PTSD	Vietnam	43	Legal secretary
Rose	83	White	Colon cancer	WW II	65	Chef
Beverly	64	White	Multiple sclerosis	Vietnam	41	Caregiver
Catherine	75	White	Parkinson's disease	Vietnam	22	Teacher

Interviews

I used a semi-structured interview script containing three central questions and several probes (Appendix E). Each interview was conducted in the participant's home without the husband present. Interviews began with a general background of the couples' history (how they met, when they were married, and details of the husband's military deployment). The interviews unfolded as conversations, with the interviewer repeating or synthesizing the participant's statements to verify what had been said, and interjecting questions as appropriate to support the flow of the interview. Janesick (2000) uses the metaphor of a dance, in which the interviewer initially follows structured choreography and opens to more improvisation as the interview (dance) unfolds. The initial structured questions regarded the three main points: 1) history of the relationship; 2) caregiving in the relationship post-combat; and 3) the wives' current experiences caring for a husband with dementia. Each interview lasted about one and a half hours and was recorded using an MP3 recording device. Written notes were also collected during the course of the interview, and debriefing field notes were completed immediately after each interview. These notes included pertinent clarification of the interview experience as well as the researcher's general observations.

Data analysis

Interviews were transcribed and the text was read repeatedly to ensure a general understanding of the content. Preliminary codes were determined, and chunks of data were organized accordingly. Coding was reviewed for concurrence with an external reviewer to enhance rigor. The codes were collapsed several times to consolidate the information and provide the opportunity to group them into categories. The codes were organized into two main categories of subjective experience: that of the dyad (*relationship*), and that of the caregiver (*caregiver experience*). The categories were used to organize the themes that evolved from collapsing the codes. The primary methodological approach was qualitative description, employing content analysis procedures. According to Sandelowski (2000), this method of deriving codes from the data allows for a summary of an event in the ordinary terms of the event.

Findings

Themes within each of the two main categories of *relationship* and *caregiver* clustered around experiences within the dyad and relationship or for the individual caregiver. Themes within each main category were as follows:

Relationship

1. Rule of silence: pertains to the husband's avoidance of or reluctance to speak about his combat experience
2. Navigating emotional land mines: describes how the wives and

husbands made adjustments to accommodate for the rule of silence

3. **Bond of love:** pertains to the emotional connection that exists within the dyad and how wives continue to feel the bond

Caregiver experience

1. **Managing painful feelings:** describes how wives perceived and related to their feelings in regards to the husbands' silence and the subsequent changes in relationship
2. **Fulfilled or compromised dreams:** relates to the dreams or future plans that wives sacrificed for their husbands or were able to fulfill
3. **Social support:** concerns the network of support upon which the wives feel they are able to rely
4. **Adaptation to a new role:** describes the ways in which wives recognized, adapted to, and integrated their roles as caregivers

I. Relationship

Rule of silence

One of the most salient findings across the four interviews involved the dyad's processing of the combat experience. In general, the husband was reticent to speak of his past. When asked about his experiences he volunteered very little information, if any at all. While the husband was deployed, letters from overseas contained few facts about what was actually happening. The soldier's everyday experience was often encapsulated by simple comments such as "I'm fine, don't worry about me." Furthermore, lack of disclosure of wartime events and personal reactions persisted into the

relationship once home.

Wives reported a general distance, or being walled off, from their husbands' emotional existence. The absence of communication at home manifested as a reticence to share to a complete rule of silence in the household. As Marie reflected:

[When he came back from the war, he said], 'It's over, don't want to talk about it, don't want to deal with it.'...He just kept saying, 'that chapter in my life is closed. I'm not going to talk about it.'

Further, hiding feelings was expressed as a mechanism by which the husbands both dealt with their own experiences and adapted to the demands of the marital relationship and family responsibility. Wives reflected on the notion that their husbands actively hid their feelings about their combat exposure. Beverly acknowledged that in his letters from Vietnam, her (then future) husband:

...never talked about being afraid, and I knew he had to have been afraid. He never talked about not coming home.... He hid a lot, I think. I think he did. He probably didn't want to upset me in any way or add any worry to our family.

The rule of silence was not usually perceived as a source of conflict in the marital relationship. For the most part, the wives respected their partners' spoken or unspoken wishes to refrain from probing into the past. The husband's stoicism was seen as part of who he was, and was not questioned. It may have been overshadowed by his general affect: "He was always so sweet. He never

talked about being in the war...I could tell that he really didn't want to talk about it, so I kinda let it go.”

It is not clear how or whether the communication, or lack thereof, directly impacted the marriage. Again, the rule of silence was respected, whether a conversation involved the combat experience or everyday matters. Catherine's husband had been a high-ranking military official who was reportedly very open about his war experiences from the “leadership perspective.” Nevertheless, she noted:

I learned, don't ask him too much, just wait...If it was really good, he couldn't wait to tell me [about his day]. But if it wasn't so good, if he starts telling me, then he's living it all again...So just wait for what he feels like telling...just let him talk about what he feels like talking about.

Wives filtered the content of conversation with their husbands in order to avoid triggering emotionally charged memories. Nonetheless, the content surfaced in other ways. In spite of the tendency to gloss over hardships, some husbands were also described as being “possessive” or having an “obsession” to take care of and provide for their families. At times, psychological stress and anxiety surfaced as nightmares:

He would have those dreams and his body would be soaking wet and he'd be shaking. And I'd hug him or hold him, but he wouldn't talk about it. And the next day he wouldn't talk about it. So I felt shut out... I felt frustrated that I couldn't be there.

Couples utilized multiple efforts to steer clear of any heated emotional content

from the traumatic experiences. Regardless of the effort put forth, all wives were aware of underlying anguish that could confront them at times.

Navigating emotional land mines

The period of transition between behaviors related to combat experiences and those related to dementia was not clearly delineated. In some cases, the transition was marked by a major life milestone, such as the couple becoming “empty nesters”, or the veteran’s retirement. The veteran’s past may have come into play more notably at this point. Marie observed that:

...It’s almost like he put it in a little box, and it stayed there for a long time, and then the box started to crack open. And when he was first working...I was working, we had four kids, we had a very active lifestyle...It was almost like he could push it back because there was a lot of stuff going on. But as the kids started leaving the home and things were quieter, his parents passed on, it was like he couldn’t anymore. It just kind of burst into the forefront.

The PTSD symptoms in this case appeared to be amplified with the onset of dementia, but some of the behaviors are similar: disturbed sleep patterns, agitation, wandering, moving furniture and objects in the house, making it difficult to see whether PTSD symptoms persisted. In this case, the change in lifestyle with the husband’s onset of dementia led to feelings of resentment for both parties. When Marie’s husband retired, there were more demands on her in terms of his time. As his cognitive status began to deteriorate, his need for care became a priority. Marie felt that her husband was

jealous of her job, especially after his retirement: “He was really resentful of it and he was really angry with me.”

Rose wanted to protect her husband from certain adverse emotional reactions. In one instance, her grandson expressed a desire to bond with and understand his grandfather’s war experiences by watching the *Band of Brothers* series together. Rose’s reaction was to prevent her husband from watching the movies, aware of the potential emotional impact. When the veteran actually watched the series, Rose stated that “he cried for three days...And now he seems more free to talk about it.” She reported that it became clear to her at this point that his silence was his attempt to forget about his past, but perhaps confronting it was more helpful.

The turning point in these relationships appeared to be when the husband’s cognitive status, behaviors, and, especially, the ability to handle previous roles and responsibilities within the household began to decline. However, it was not recognized as a clear transition. Marie stated that her husband “was always a take-charge person that did everything.” She reflected that she did not realize the loss of his role until later, when it became clear that he was unable to perform the tasks that were part of his regular household routine, and his contribution to household duties declined remarkably.

Couples adapted to their circumstances as a unit, as expressed by Rose “I deal with it, we do it together.” Individually, these wives saw their personal experiences and what they learned through the caregiver role as valuable, and felt that their knowledge might benefit others. Catherine

considers writing a book on her experience in order to share valuable tips and information with others in similar situations. Marie feels that the adaptation to her situation was almost second nature:

The learning to cope part of it is, I think, automatic. You just find ways. I mean, how did anybody get through their life? How does anybody – someone with a handicapped child, or an alcoholic husband...we all have mechanisms.

While the wives were charged with the actual demands of caregiving, they found satisfaction and meaning in the role because it was incorporated into the couples' daily lives.

Participants consistently reported shared meaningful occupation as an adaptation in response to the changes in their relationships. The wives sought activities that the couple could continue to enjoy. Rose and her husband, for instance, watched old television programs that they used to enjoy together:

A highlight of our life is *Lawrence Welk*...he'll say to me, 'is today Saturday?' I say, 'Yes, it's *Lawrence Welk*, and he'll say, 'what's the snack for *Lawrence Welk*?' Well, that's a way to get him to eat. And we sit there and we sing. I said if someone comes by and hears us they're going to take both of us away (laughs)!

Rose found a way to include one of the important tasks of caregiving – feeding – in spending time with her husband, which she found emotionally fulfilling. Other wives mentioned sharing meals and engaging in simple daily activities such as dressing and grooming as ways in which they could care for their

husbands while connecting with them in familiar, intimate ways.

Bond of love

The bond of love that exists between the partners was acknowledged during the interviews, and a strong sense of each wife's commitment is evident within all the relationships. Compassion for the husbands was a common attitude, stated in terms of feeling "sad that this had to happen to him" or acknowledging that his "spirit is still there.... it's just been impacted by this horrible disease." There was a sense of estrangement for Marie, as in "he's here but he's not here." In Beverly's case, the bond was broken with the husband's early cognitive loss: "I think it took us a long time to – for him to remember that he still loved me, and for me to find a new kind of love. Because it wasn't the same. He was a different person."

In contrast, when the bond of love was felt as the main connection, loss was expressed as nostalgia. Rose said, "[we] can't even have a good tiff anymore. I didn't think I'd miss that (she laughs)." Dementia was not seen as a barrier to the closeness that these wives felt with their husbands. In fact, the love was described as being "apparent" between the partners, and was felt more strongly than any emotional distance that may have existed.

Some wives expressed a sense of gratitude in reflecting on their years of marriage and the inevitability of death. Marie felt that she'd been given "extra time" with her husband despite his dementia, while Rose felt simply that she and her husband had "had a good life together, enjoyed everything together, and now we're going to continue to be together." The

wives recognized that they might lose their husbands in the future, but did not appear to be preoccupied with the notion. Rather, they felt that the time they had with their husbands now was precious.

Rose shared a poignant story about her husband talking about their gravestones to their children:

When we bought our plot, he said, ‘you’re not going someplace and me [to] another. We’re going together, you know.’ And so, we bought a plot. He said the other day—he amazes me, we could always have a nice conversation—‘we tell the kids what we want.... You tell them I want ‘together forever.’...He’s so sweet.

Rose was able to interpret this comment as her husband’s desire to be together forever because she knew him to be a loving husband. Wives who believed in the strong, loving bond they had had with their husbands prior to dementia also mentioned being able to speak for their husbands or to “read his mind.”

Catherine stated that “something that he says to you that’s just so sweet or so kind or something, in one day, inspires you.” The wives celebrated having small glimpses of the men they married.

II. Caregiver experience

Managing painful feelings

Feeling hurt was a common sentiment among those women who recognized their husbands’ reluctance to share, but it was not always realized in the moment. Beverly described the main focus of their relationship as caring for her husband, who was diagnosed with multiple sclerosis six months after

returning from Vietnam. She did not realize until much later that her husband's silence had had any emotional repercussion for her. In fact, it was not until the interview that she put the pieces together and had some insight as to being left out of a significant portion of her husband's life. Upon having this revelation, Beverly tearfully expressed that the realization was "hurtful," but she also expressed feeling grateful for the opportunity to see her experience in a different light.

Another manifestation of the emotional impact on the wives is seen in references to feelings of resentment. Beverly described being resentful of her husband's support group at the Veterans Administration (VA) Medical Center, stating that she felt it was his "VA secret." Furthermore, because he required her care within months of returning home from war, her expectations of his role in their relationship were decimated from the beginning:

I thought I was going to get him back. I thought – yeah, he's sick, but he's going to be ok. We'll get him back. But as the time went on I realized I wasn't going to get him back. He's not the same person, and he's never going to be the same person. Even now I get mad at myself, it's like, oh my God, I want more than he can give.

Beverly's realization created an additional strain and may have added to her feelings of resentment. She also noted feeling hurt that her husband "found comfort in the VA, where he didn't find comfort with me."

Marie expressed a sense of feeling hurt that "he wouldn't talk to [her] about [his combat experience] but he wouldn't talk to anyone about it." All

individual caregivers reflected on some sense of hurt and pain dealing with their husbands post-combat. However, none was willing or able to directly confront this pain with their husbands. Further, the wives never allowed their painful feelings to interfere with their caregiving and other role responsibilities.

Both Beverly and Marie expressed acceptance of their situations and the ways they were able to manage them. Marie stated, “It’s ok to have a day when you’re really frustrated or really angry. And people would say that to me. You can’t be Sally Sunshine all the time, you’re going to have bad [days].” Beverly felt that once she accepted that her husband was not the same person and could not communicate with her the way he once did, she was “a heck of a lot better off.” She also recognized that she had to “accept things the way they are.” Thus, acceptance seemed to be an effective strategy for these two women to support their roles as caregivers.

Fulfilled or compromised dreams

Wives told of dreams that they were either able to fulfill or had to sacrifice in order to accommodate their husbands’ needs. Marie and Catherine both loved their jobs. Marie reluctantly left her position as a legal secretary in order to fulfill her husband’s wish to retire in Florida. Conversely, Catherine was able to keep her job as a teacher until she and her husband decided to retire. Rose worked in order to “make [their] dreams come true”; she saved money from her job as a chef so that she and her husband could travel through Europe together. Beverly had the dream of how marriage might be, which she felt was

“shattered” by her husband’s illness.

The concept of dreams overlaps with changes in the wife’s lifestyle, particularly around her job or career. Wives worked jobs they loved in order to maintain independence and gain personal satisfaction. Sacrificing her career in service of her husband’s dream was a difficult adaptation for Marie, who had worked the same job for nearly thirty years. By contrast, Beverly was unable to work due to the expectations that she would care for her husband and children full-time. Consumed by her role as caregiver, she was unable to consider gainful employment outside the home.

Social support

When asked whether there were other women in their situations during the years surrounding the war, all participants reported having had friends who either dated or married servicemen. Beverly’s husband was the only one out of a group of friends who was drafted into service. Though she found support in her family, she felt alienated from her group of friends: “Other girls were going on ski trips, they were dating, and I was waiting for my man [to come home].” Catherine was a military wife and felt her strongest support by taking on responsibilities and working, which was also her way of asserting independence.

The factor that set these wives apart from others was the lack of communication regarding their husbands’ combat exposure. Although they may have been able to relate to the simple fact that other wives had husbands in the service, each wife perceived her situation as unique. This perception

interfered with her ability to completely relate with other wives within her social circle. Marie felt isolated socially because of her claim that other veterans “talked about [their Vietnam experience] all the time.” Catherine, on the other hand, was an officer’s wife who was committed to the responsibilities of that role. She described an understanding within her marriage that her husband would share his thoughts or feelings when necessary. Being dutiful in her role, she agreed to follow his lead.

The idea of access to social supports carried forward when the dementia caregiving demands were added. Wives felt strong support from family members and friends, regardless of whether they felt they could relate directly to others in a similar situation. Adult children were recognized as the strongest sources of direct support in all four cases. Both Beverly and Rose felt fortunate to have close friends living next door or across the street. Informal social support was seen as necessary to keeping the husband at home (as opposed to moving him to a nursing home or other facility). Marie was “not ready to give up on him.” Wives felt that husbands thrived in the comfort and familiarity of their own homes, as Catherine expressed: “I feel like that’s what’s keeping him alive.” Wives also felt that they wanted to continue their roles as primary caregivers for their spouses.

Support groups, on the other hand, were viewed with mixed responses. Beverly felt alienated from others in the support groups when her husband first fell ill:

I’m 24 at the time...they seemed older, they might have been 35,

maybe...And I'm thinking to myself, what am I doing here? There was nobody there that I could relate to. So it really didn't help us at all.

Catherine, meanwhile, felt that her inclination to take care of others would override the support she would actually receive from the group.

Adaptation to a new role

The onset of dementia symptoms resulted in the increase in caregiving responsibilities, and a shift in role that marks a transition for the wives. Marie described feeling a sense of disorientation: "I said...what's happening to me?" Rose felt it was a surprise, that the shift happened "before I knew it. I was Indian chief. It's not the fun I thought it was going to be. You know, at this age. But, I do it." The wives described feeling cared for previously, and that decisions were made jointly. Suddenly, those responsibilities fell squarely on their shoulders, resulting in a sense of having to "take care of everything" or being "on my own."

Adaptation to the shift in roles and responsibilities was influenced by societal norms and expectations. For instance, Rose assumed traditional responsibilities from the very beginning of their marriage: "I had to manage the household, make sure we had three meals a day." She did not view her husband's emotional silence or other behaviors as problematic. She related his extravagant, "obsessive" need to take care of his family to childhood deprivation and not to any experience he may have had in war. Later, she did not view her dementia caregiving responsibilities as a burden, because they "were going to be together and...were going to make it."

This sentiment may be understood by the societal norms of this generation. The younger wives—particularly Marie and Catherine—had more expectations of maintaining independence in their roles. Sacrifices like giving up a job, for instance, appeared to be especially challenging. Resentment grew for Marie under the expectation that she would retire once her husband retired. Later, when she realized that he was in the beginning stages of dementia, she felt guilty. The common thread among these wives is a feeling of responsibility toward their husbands, whether it was considered a given or out of a sense of duty to him for his suffering.

The important functions of managing a family and a household took precedence over relating to situations in the husband's past. When the husband's affect shifted into depression or sadness, it went unaddressed. Even when clear symptoms of combat trauma such as nightmares or delusions surfaced, the couple continued their daily occupations. According to Marie, as her husband displayed increasing PTSD symptoms, "These things started to happen and it was a time when we had four kids, the kids were in college. It was just kind of like, you dealt with it."

Overall, the combat experience was folded into the everyday fabric, as Marie describes: "We'd have two or three weeks when things went very smoothly, then he'd get agitated, he'd be up all night, or he'd be struggling with dreams or delusions, but we kept on track." In all but one case, the couples had met at an early age, and their individual roles within the household appeared to be dictated by societal norms. The wives considered

themselves the primary caregivers for their children and managed most of the household chores such as laundry and cooking. In addition, the wives organized the family around their husbands' work schedule. Marie, whose husband became a police officer after leaving the military, stated, "everything was pretty much geared to when he was working and what he was doing." Husbands considered themselves the "breadwinners." Beverly's husband lost this role almost immediately upon return from service due to onset of multiple sclerosis, but he maintained tasks that Beverly referred to as "doing the manly thing"—e.g., shoveling snow or mowing the lawn.

Generally, the wives indicated that caring for their husbands was well within the scope of their marital duties. In reflecting on her experiences, each wife felt that she had had a good life with her husband, and was able to see the caregiving role as an extension of their relationship. Furthermore, wives reflected on the idea that their situations could be worse. Each wife articulated an example that she felt could be more challenging—divorce, losing a child, or more severe problems related to dementia. Wives experienced satisfaction from successfully meeting the demands of their roles, indicating that the caregiver role was "natural" for them. Problem solving was mentioned as an enjoyable factor for Catherine, while for Rose, after so many years of marriage and managing the household, caring for her husband was not an overwhelming challenge.

Finally, self-care was an essential factor in wives' adaptations to and satisfaction in their roles as caregivers. All four husbands attended day care

programs, which afforded the wives time to be alone in their houses, run errands, see friends, or relax. They mentioned having lunch with friends, playing golf, or reading as ways to enjoy themselves or release their cares for a time. Rose named cooking as her “first love...I cook myself out of tears, out of happiness, out of everything.” Beverly, however, felt a sense of weariness in her role that led to apathy about self-care. Her duties as a caregiver had consumed and worn her down since the early days of her marriage. She claimed having done things to take care of herself earlier, but these were superseded by concerns about continuing to meet the demands of her role.

Discussion

Effects of communication barriers over time

Avoidance of emotionally charged situations and conversation is a characteristic symptom of PTSD (American Psychiatric Association, 2000), and has surfaced as a theme in research that explores the impact of PTSD on the marital relationship (Evans, McHugh, Hopwood, & Watt, 2003; Galovski & Lyons, 2004). In our findings, we interpreted avoidance as the “rule of silence.” In the four cases we explored, only Marie indicated feeling that her husband intentionally avoided the topic of his combat experience. Most often, the wives did not recognize avoidance as such. The combat experience was incorporated as a part of the marital and family history, but was not considered a central focus. Couples carried out the responsibilities of their daily lives, managing households and raising families. Wives reported being more open with their thoughts and feelings than their husbands. They described

themselves as being “up front,” whereas husbands appeared to “bottle up” their reactions.

The stories that husbands told seemed tinged with an air of emotional distance. Catherine, whose husband was a high-ranking official, claimed to be “well-versed” in her husband’s war history, but it appears that he described them to her matter-of-factly from the perspective of his leadership role. Similarly, Rose recounted her husband’s stories in a way that lacked the emotional charge that the experience itself likely held. Their husbands may have distanced themselves from the impact of their past, and the wives followed suit, as evidenced by Rose’s tendency to protect her husband from the emotional reactions that recalling his stories would trigger. This interpretation is related to Lyons’ (1999) findings that that wives of veterans avoided conflict with their husbands in order to cope with the stress of the situation. On the other hand, their husbands may have been protecting their families from the potential impact of their experiences.

While the two main categories of findings relate to the dyad and the caregiver, the issue that binds them together is the wife’s experience. Her husband’s combat trauma, whether acknowledged or not, in combination with his dementia, influence her caregiver role and her perception of it. The wives interviewed for this study acknowledged that their husbands’ combat exposure had an impact on their relationships, whether adverse, positive, or neutral, though it may not have been recognized at the time. Later, wives did not feel a clear transition into their new roles as the husband’s dementia

progressed. This may relate to the concept of *continuity* in dementia care as put forth by Walters, Oyebode, and Riley (2010). In their study, women caring for spouses with dementia who had better adjustment outcomes felt a stronger continuity between the past and present. For the wives in the present study, continuity may be less obvious because of the ambiguous nature of the factors at hand (e.g., how communication barriers affected the transition). Further research is warranted to reveal whether the ambiguity of the role transition is generalizable to other spouse caregivers.

It is difficult from this study to determine whether the rule of silence directly impacted the way these women cared for their husbands later in the course of their marriage; however, it can be said that there were adjustments within the relationship (in terms of communication) as well as individually (in terms of managing feelings around the silence). When asked whether they felt any additional sense of burden in the household due to their husbands' combat experiences, wives felt that they had to make compromises, either emotionally or pragmatically, based on the husband's silence. This led to a feeling of being "rejected" or "hurt." However, it was noted that the veterans tended to avoid discussing their experiences with anyone. This seemed to lessen the emotional hurt experienced by the wife and reinforced the rule of silence, causing it to become an accepted piece of the fabric of their daily experience.

Gaugler, Kane, and Newcomer (2007) define resilience as the caregiver's resistance to stress in the face of care demands. Their study focused on extrinsic factors in dementia caregiving (e.g., context, outside

resources and supports) as the key components of resilience. Gaugler, Kane, and Newcomer note that a potential limitation in their work is a lack of emphasis on key intrinsic variables. Our study describes the role of intrinsic factors in supporting the caregivers' resilience. Caregivers employed intrinsic factors such as perseverance and tolerance to accommodate to their husbands' silence or emotional distance. While the husbands' silence was not always recognized as a problem, it set the tone of communication within the dyad. As husbands were reticent about their own experiences, the wives adjusted accordingly, seemingly without argument.

In general, the marital relationships were reported as good, with only small arguments peppering the flow of their daily lives. A strong bond existed between the dyads, upheld by the framework of marriage: commitment, responsibility, family, and love. These fundamental elements endured through the progression of the relationship, and wives did not consider their duties, whether in the context of raising a family or later as caregivers, to be burdensome. Rather, they were viewed as compromises that were typical of any marriage, and "just what you did." Rose expressed having had a "good life together" and went on to say that "now we're going to continue to be together," suggesting that she created or believed in a sense of resilience not only in herself, but also in the partnership, that could transcend death.

Positive and negative perceptions of the caregiving role

Though each wife described a unique experience, it was clear that they all found ways to sustain the caregiving role. It was expressed in a number of

ways—through perseverance, as in “I’m not a quitter,” and perception of support received from friends and family members. A sense of gratitude for having had a loving relationship and having been able to weather the struggles of marriage seemed to correlate positively to the energy and willingness to continue caring for the husband. Beverly described less positive perceptions of the relationship, which led to feelings of weariness. Despite reporting depression, she continued to fulfill her caregiving role and responsibilities.

Negative views of caregiving responsibilities were not present for wives who felt that their husbands had cared for them in practical matters (e.g., finances, home maintenance, etc.) through the course of their marriage. The realization of their new roles in the household may have come suddenly, but the transition was not marred by a sense of hopelessness. Beverly described having “a lot of hope in the beginning,” but as her husband’s condition not only persisted but also worsened, she understood that her role was permanent. Her attitude towards it was heightened by the many expectations she had as a newlywed. She emphasized that, as time went on, she felt as if her husband were a different person than the one she married.

In contrast to Beverly, the other wives’ attitudes towards their roles and satisfaction in the relationship was equated with the quality of their marriage, and, the integrity of the husbands’ previous (traditional) role in the household. A “good” relationship led to fewer feelings of burden. When the feeling of love was strong, caregiving was not viewed as a sacrifice. Wives felt that they would “do anything” for their husbands out of a deep sense of

commitment to the relationship. This is consistent with studies that examined the ideas of commitment and marital strength in the face of dementia (Gwyther, 1990; LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005). Furthermore, when the husband was able to offer financial security and otherwise maintain the more traditional role of breadwinner and overseer of practical matters, wives were less likely to see their relationships as deteriorating.

An indication of resilience is the wives' continued engagement in self-care practices to sustain their roles. For Rose, cooking was something she learned early as a young newlywed charged with what was seen as traditionally the "woman's" task. She also made a career out of cooking for others. Other women found cooking to be a way to gather friends (thus, support). Playing golf, having dinner with friends on occasion, going to a pool program, and reading were mentioned as ways the younger women took care of themselves.

It is love that binds these couples in the end, an undeniable connection that goes deeper than the daily responsibilities, but marked by the moments they are still able to share. The sentiment that these wives would do anything for their husbands was common. As stated by one wife, "it's love that keeps you going."

Conclusions

This study describes the accounts of four women who had the challenge of caring for husbands with dementia after integrating the consequences of their husband's combat exposure into their marital lives.

As studies on the relationship between PTSD and dementia grow, this population will require more attention. There may be a sense of alienation experienced by women in this cohort, pointing to a need for specialized support groups or programs. Future research should take into consideration the complexity of factors that impact this cohort. The caregivers in this study have more readily accommodated to the demands of dementia caregiving as a result of prior adjustments to communication and emotional issues within the dyad. Therapists working with women or men in this situation need to be aware of caregivers' levels of experience, as well as the caregivers' perceptions of their relationships and abilities.

This is the first study that focuses on the caregiving experience of wives of combat veterans with dementia. One limitation of the study is that couples were selected based on functioning, sustained relationships. The research could be expanded to include couples who divorced as a result of behaviors related to PTSD, or who have other complications adding to their circumstances (e.g., substance abuse or domestic violence). Further research is needed to focus specifically on the impact of combat-related trauma on the perceived role transitions of caregiving.

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OFFICE OF THE VICE PROVOST

Appendix A

Social, Behavioral, and
Educational Research
Institutional Review Board
FWA00002063

Re: IRB Study # 1011017

Title: The Caregiving Experience of Wives of Veterans with Combat-Related Trauma and Dementia

PI: Teresa Czepiel

Faculty Advisor: Scott Trudeau

IRB Review Date: 11/18/2010

November 29, 2010

Dear Teresa,

The Institutional Review Board (IRB) has reviewed your response to the conditional approval for the above referenced study. The response was received in our office on 11/28/2010.

This protocol now meets the requirements set forth by the IRB and is hereby approved. Approval is valid from the date of this letter for a period of one year from the original IRB Review Date and expires on 11/17/2011.

Enclosed you will find stamped consent forms and other study materials that show the date through which these materials are valid. Only copies of these stamped consent forms and materials may be utilized for conducting your study.

This protocol has been approved for a total of 10 participants for the duration of your study.

Any changes to the protocol, consent forms or study materials must be submitted to the Office of the IRB for approval by completing the *Request for Protocol Modification* form. In addition, all Adverse Events and Unanticipated Problems must be reported to the Office of the IRB promptly, and by utilizing the appropriate reporting forms.

Investigators are required to submit a *Request for Continuing Review* or a *Request for Study Closure* six weeks prior to the expiration date of the protocol.

Please know that the PI is responsible for all information contained in both this letter and on the Investigator Responsibilities Sheet. If anything is unclear or if you have any questions, please contact the IRB office at (617) 627-3417.

Sincerely,

A handwritten signature in black ink that reads "PP Yvonne Wakeford".

Yvonne Wakeford, Ph.D. IRB Administrator

Appendix B
TUFTS UNIVERSITY
BOSTON SCHOOL OF OCCUPATIONAL THERAPY

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

**The caregiving experience of wives of veterans with combat-related trauma
and dementia**

Principal Investigator: Teresa Czepiel, OTS

INTRODUCTION

You are being invited to take part in a research study to describe the experiences of wives of veterans with combat-related trauma who later developed dementia.

Participation in this study is entirely voluntary. You can stop taking part in this study at any time. Your decision will not affect how you are treated by the investigator or at Tufts University.

Please read all of the following information carefully. Ask Teresa Czepiel (the Principal Investigator) to explain any words, terms, or sections that are unclear to you. Do not sign this consent form unless you understand the information in it and have had your questions answered to your satisfaction.

If you decide to take part in this research study, you will be asked to sign this form. You will be given a copy of the signed form to keep for your records. It has information, including important names and telephone numbers, to which you may wish to refer in the future.

If you are eligible and agree to be in the study, the Principal Investigator may still choose to stop your participation in this study if she thinks it is in your best interest.

If you have questions about your rights as a research study subject, call the Tufts Medford Campus at (617) 627-3417. The Institutional Review Board (IRB) is a group of people who monitor research for safety and protection of people who take part in the studies. Federal law requires the IRB to review and approve any research study involving humans. This must be done before the study can begin. The study is also reviewed on a regular basis while it is in progress.

This research study has been reviewed and approved by the IRB of Tufts Medford Campus.

PURPOSE OF STUDY

The study aims to describe the experiences of a growing population of wives caring

for older veterans with dementia. Many soldiers and their families were affected by experiences during the war. Many of these same veterans also developed dementia, and there is growing research on the possible connection between the two conditions. This study will help us understand these connections better.

The study is being conducted as part of a Master's Thesis through the Boston School of Occupational Therapy at Tufts University's Medford campus. The interview in which you are being invited to participate will take place in your home or in a location that is convenient to you.

This is a small study consisting of up to ten (10) total participants.

PROCEDURES TO BE FOLLOWED

To participate in the study, you will be asked to answer questions in a one-to-one interview with the principal investigator. We will meet only one time for the interview which will last approximately 90 – 120 minutes. Your total time of participation in the study will be the time it takes to complete our interview visit – approximately 2 hours. The interview will be recorded using a digital recording device.

RISKS

There are few risks associated with this study, as you are free to respond in any way you wish to the questions involved. Though we do not anticipate that you will experience any serious psychological discomfort, the Principal Investigator is available to offer support and referrals to other professionals as necessary.

All material discussed during the interview is confidential and will be kept within the limits of the study. This means that no person outside the study will have access to any information about you or your partner, or anything that comes up during the interview.

BENEFITS

There is no financial compensation for participating in this study, and no known benefits.

WHOM TO CONTACT

Should you have any problems or questions at any time, please contact the Principal Investigator:

Teresa Czepiel
(413) 313-6274 (cell and home)

The mentor for this project, Dr. Scott Trudeau, has 25 years of experience in the field of occupational therapy and extensive experience working with older adults with dementia and their caregivers. He can also be contacted if you feel the need at 617-627-5930. His voicemail is private so feel free to leave a message.

COSTS

There are no costs associated with participation in this study.

PRIVACY AND CONFIDENTIALITY

If you agree to take part in this research study, your personal information will not be shared with any outside party without your express permission, given in writing. This will not be necessary unless the law requires it. The Institutional Review Board of Tufts Medford Campus may check records that identify you. This might include the informed consent form you signed. The records of this study might also be reviewed to make sure all rules and guidelines were followed.

PARTICIPANT'S STATEMENT

I have read this consent form and have discussed with the Principal Investigator, Teresa Czepiel, the procedures described above. I have been given the opportunity to ask questions, which have been answered to my satisfaction. I understand that any questions that I might have will be answered verbally or, if I prefer, with a written statement.

I understand that I will be informed of any new findings developed during the course of this research study that may affect my willingness to stay in this research study.

I understand that my participation is voluntary. I understand that I may refuse to participate in this study. I also understand that if, for any reason, I wish to discontinue participation in this study at any time, I will be free to do so.

If I have any questions concerning my rights as a research subject in this study, I may contact the Institutional Review Board at (617) 627-3417.

I have been fully informed of the above-described study with its risks and benefits, and I hereby consent to the procedures set forth above.

I agree to having the interview audio recorded: yes no

Date

Participant's Signature

I have fully explained to _____ the nature and purpose of the above-described study and the risks that are involved in its performance. I have answered all questions to the best of my ability.

Date

Principal Investigator or Representative's Signature

Appendix C

Pre-interview Telephone Screening

1. Are you fluent in English?
2. In which war did your husband serve? How long was his deployment?
3. Does your husband have dementia, and would you consider yourself the primary person caring for him?
4. This study is intended to describe the experience of wives whose husbands showed symptoms of post-combat stress. Examples of symptoms include nightmares, angry outbursts, or avoiding talking about their experiences. Would you say that you fall into this category?

Appendix D

Interview Script

1. If you were married before the war, what was it like in your household before your husband was deployed?

Probes:

- Did you have a particular role?
- What kinds of things did you do in the household?
- Would you consider yourself similar or different to other wives at that time?

2. What was it like for you at home after the war?

Probes:

- (If you were a couple before the war) Did you feel that your relationship changed? If so, how?
- What responsibilities did you have?
- How did your partner act?
- Did your partner talk about his/her experiences during the war?
- What kinds of behaviors did you notice?
- Did these behaviors have any impact on your life and role in the household? If so, can you describe how they impacted you?
- What was your social network like at that time? Did you have support from friends/family who shared a similar experience?

3. How is it living with your partner now?

Probes:

- Have your roles in the household changed? If so, how?
- How, if at all, has your relationship with your partner changed?
- What is your experience of caring for your partner currently?