



Hidden Costs

Invisible

Contributions

Wounded Veterans, Wounded Families

In the fall of 2007, we completed a national telephone survey of younger Veterans released from active duty with high levels of disability, and of the family members who support them. The results of this survey are stunning. Family members who support these younger high-needs Veterans are at substantially higher risk of poor financial, social and health outcomes than any other group of caregivers we have examined in more than 20 years of research on families and care. The high levels of need evident in the data and the voices of these families led us to the title for this report.

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Hidden Costs/Invisible Contributions

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Wounded Veterans, Wounded Families

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Wounded Veterans, Wounded Families

Executive Summary

This report provides the first view of experiences of families of Veterans with high levels of service-related disabilities. Information in this report comes from a national telephone survey conducted to evaluate the experiences of family members and friends who support adults with disability. The survey was conducted as part of the Hidden Costs/Invisible Contributions (HCIC) research program based in the Department of Human Ecology at the University of Alberta, in partnership with Veterans Affairs Canada.

The sampling frame for the part of the study reported here included all Veterans between 19 and 65 years of age with a high level of service-related disability assessed by VAC as between 78% and 100% total body impairment. Letters of invitation were sent to every Veteran in this sampling frame (1059). Between January and October 2007, the Population Research Laboratory at the University of Alberta conducted telephone interviews with 142 Veterans and 115 of their main supporters who had responded to our invitation to participate. The survey included questions about health and functional status, duration of disability, type and amount of support provided/received, impact of support on self and family.

Living with disabilities

All Veterans who participated in the survey had been released from active service with a high level of disability that has resulted in longstanding and complex problems. All were age 65 or under. Approximately 30% were between 25 and 44, while almost 40% were between the ages of 45 and 54.

Supporting Veterans with disabilities

Supporting a Veteran with high levels of disability is a long term process. Almost 40% of spouses had been providing support for between 10 and 19 years. Another 24% had been providing support for more than 20 years. They were investing many hours in these helping tasks: 55% reported spending 5 or more hours *every day* helping the Veteran.

Economic consequences: "The financial cost alone is tremendous"

Like the disabilities of the Veteran, care is chronic. Lives are changed as a result of providing such high levels of support over many years. Families experienced high levels of economic and non-economic consequences as a result of the disabilities of the Veterans and the support they provided. Spouses' employment was often affected by providing high levels of support over the long term. Employment impacts are important because they affect the short and long term economic situation of families. In the short term, families' income and benefits may be reduced. In the long term, retirement pensions and benefits, as well as ability to save for retirement, are compromised.

There were dramatic changes in some families' financial situation as a result of supporting the Veteran. The cumulative effect of lost wages and benefits and extra expenses is profound. More than 40% of spouses said they were earning less money and experiencing financial hardship; and almost as many (35%) were concerned about being able to provide adequately for their families' financial futures.

In addition to long term financial losses because of employment, approximately 60% of supporters had also incurred extra expenses for the Veteran—mainly for his medications, and for travel or transportation. For many, out-of-pocket expenditures were modest, but for 16% they exceeded \$5,000

in the past year. These findings foreshadow the potential for lifelong economic costs for families of a Veteran with service related disabilities.

Health and social consequences: "The non-financial cost, you can't count it"

The health and social consequences resulting from supporting the Veteran were equally common and worrisome. While less tangible than economic costs, they have a powerful impact on supporters and their families. The majority were exhausted, did not get enough sleep, and lacked time for any personal activities. Not surprisingly, most also said that their health was affected. Families suffer as a result: 53% said that they paid less attention to other family members, and that family relationships had been strained. There also is evidence of potential isolation of these families.

Services: "It doesn't reveal struggles for support"

Services from the public or non-profit sector can help off-set the stresses of supporting someone with a serious disability. However almost half (48%) of the supporters of these Veterans said they needed assistance that they did not have. Approximately 67% said they lacked the help they needed to continue to care for the Veteran, an indication of the fragility of such families.

Chief among the reasons for lacking needed supports is cost. More than half (57%) said that supports were too expensive or not covered by insurance. Smaller proportions said that supports were not available in their area (44%) or that they did not know where to get help (36%). More than one-quarter (28%) had applied for supports but had been turned down. In all, resources of these families were being stretched with little other help available.

Support from Veterans Affairs: they don't include the family"

This study did not include questions about impact on families nor about support they have to manage changes in their lives. Yet comments indicate that some caregivers felt that they and their families are invisible. They worried not only about their ability to sustain support to the Veteran, but about the impact of long term disabilities on the rest of the family.

Young people in an old culture: "we seem to be the only young ones around"

Supporters also noted the difficulty of being a young Veteran with high levels of disability. They did not expect to be dealing with problems that they associated with later life. They felt that groups like the Legion and VAC were designed for traditional, older Veterans.

Next steps: Responding to the needs of families and Veterans

Supporters of these Veterans with high levels of disability are far more likely than the general population of caregivers to have reported almost every one of the major categories of economic and non-economic consequences of care. As a result, high proportions of supporters reported financial insecurity, stressful lives and low levels of life satisfaction. They worry about their ability to sustain care for the Veteran. And they worry about their families whose lives have been changed profoundly.

The strongest message in these findings is that families have suffered as a result of the service-related disabilities of the Veteran. For this new generation, the VAC mission of providing exemplary service to Veterans *and their families* has never been more important.

Wounded Veterans, Wounded Families

“The whole family is hurt by his situation”

The Backdrop

The mission of VAC is “To provide exemplary, client-centred services and benefits that respond to the needs of Veterans, our other clients and their families, in recognition of their services to Canada; and to keep the memory of their achievements and sacrifices alive for all Canadians.” In order to realize this mission VAC needs to understand the needs of Veterans and their families. In the last few years VAC has worked hard to learn about and address the needs of its older Veteran clients and of the family members and friends who support them. In 2006, the Gerontological Advisory Committee submitted to the department a recommendation for a comprehensive, flexible program of services called Veterans Integrated Services “designed to reach more Veterans and families, help them enhance their health and well-being, and give them access to more appropriate health and social services when they need them” (p iii).

Now attention is turning to the growing population of younger Veterans of more recent peacekeeping missions, and those who support them. The needs of family members and friends who support Veterans are critically important. They play a crucial role in supporting Veterans, both during their military service and long after, especially when their service leaves them with lifelong disabilities. Research shows that the general population of those who care for family members and friends with chronic conditions experiences a wide range of negative consequences resulting from their care responsibilities. But do those caring for younger Veterans with high levels of disability have special challenges or needs?

This document provides the first view of experiences of families of Veterans released from active duty with high levels of service-related disabilities. Families of these younger, high-needs Veterans are at substantially higher risk of poor financial, social and health outcomes than any other group of caregivers examined to date. There is an urgent need for action on their behalf.

The Survey and Sampling Frame

Information in this report comes from a national telephone survey conducted to evaluate the experiences of family members and friends who support Veterans age 65 and under who were released from active duty with high levels of disability. The survey was conducted as part of the Hidden Costs/Invisible Contributions (HCIC) research program based in the Department of Human Ecology at the University of Alberta, in partnership with Veterans Affairs Canada.

The sampling frame comprised 1059 Veterans between the ages of 19 and 65 years with a high level of service-related disability assessed by VAC as between 78% and 100% full body impairment. The disability assessment reflects the severity of the medical condition(s) and quality of life using 21 possible levels. The top five levels were used for this study. Respondents fitting this criterion were the most disabled 4% of the 28,500 Veterans in the age range who were receiving VAC benefits.

Letters of invitation were sent to every Veteran in the sampling frame (1059) in two mail-outs (October 31 and November 8, 2006). The letter stated the reasons for the study and included a consent form for a telephone survey to be administered if the Veteran and his or her care supporter wished to participate. Follow up telephone calls were conducted by VAC staff members to answer any questions that clients might have. Between December 2006 and November 2007, the Population Research Laboratory at the University of Alberta conducted telephone interviews with 142 Veterans and 115 of their main supporters. The Veterans questionnaire included questions about their health status and functional abilities, the types of tasks they required assistance with, their unmet needs, and basic demographic information. The supporters questionnaire asked about their health and functional status,

duration of the Veteran's disability, type and amount of support provided to the Veteran, and impact of providing that support on self and family. At the end of the interviews participants were asked if they had questions or comments about the survey. These responses provide additional qualitative data that set the survey findings in poignant, "life as lived" context.

Appendix A shows comparisons between the 158 Veterans who responded to our invitation to participate in this study (though only 142 interviews were completed) and the full sampling frame on the characteristics of province of residence, marital status, gender, age and health conditions. These comparisons show that the sample for this study is similar in terms of geographic (provincial) distribution, gender and number and type of health conditions. The survey sample includes more married respondents, perhaps because these Veterans are more likely than those who are unmarried to have a family member to care for them. Those surveyed also are slightly older than the sampling frame of Veterans with high levels of disability. Thus the characteristics of the sample closely represent the relevant Veteran client sampling frame, though survey participants may have lower levels of unmet need because they are more likely to have a spouse to support them.

Living with disabilities

All Veterans who participated in the survey had been released from active service with a high level of disability. They are not elderly. All were under age 65. Approximately 30% were between 25 and 44; while almost 40% were between the ages of 45 and 54. It is evident from their answers to the survey that their disabilities have resulted in longstanding and complex problems. The majority (74%) reported their health to be only fair or poor (see Figure 3). Compared with the general population of Canadians, only 11.3% of Canadians between the ages of 45 and 54 report that their health is fair or poor (Statistics Canada, 2005). Veterans live with immense challenges (Figures 1 and 2). The vast majority has long term physical and/or mental conditions that interfere with their abilities to do things at home: their mobility, their ability to walk, climb stairs, and/or reach or bend down to do simple tasks. More than half are confused or have difficulty with personal tasks such as dressing. A substantial minority has difficulty seeing, hearing or communicating. It also is clear that all or most have multiple disabilities.

Figure 1

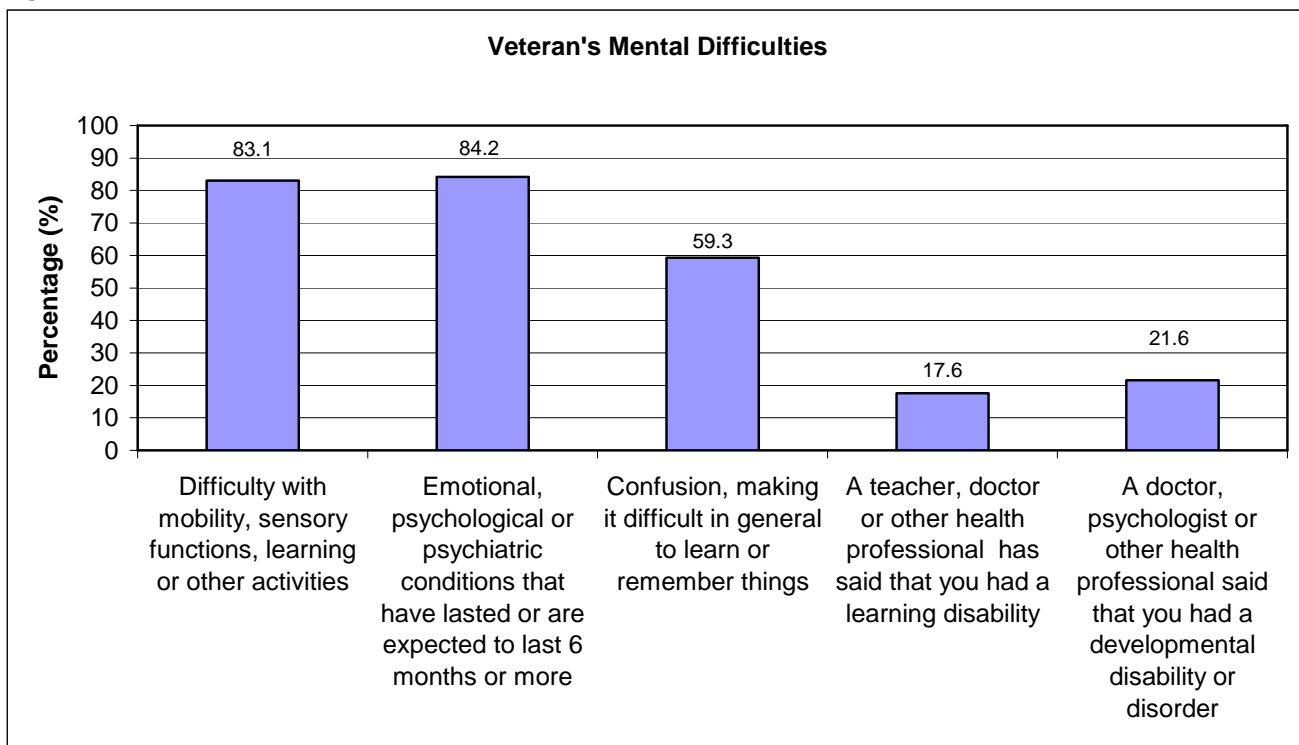
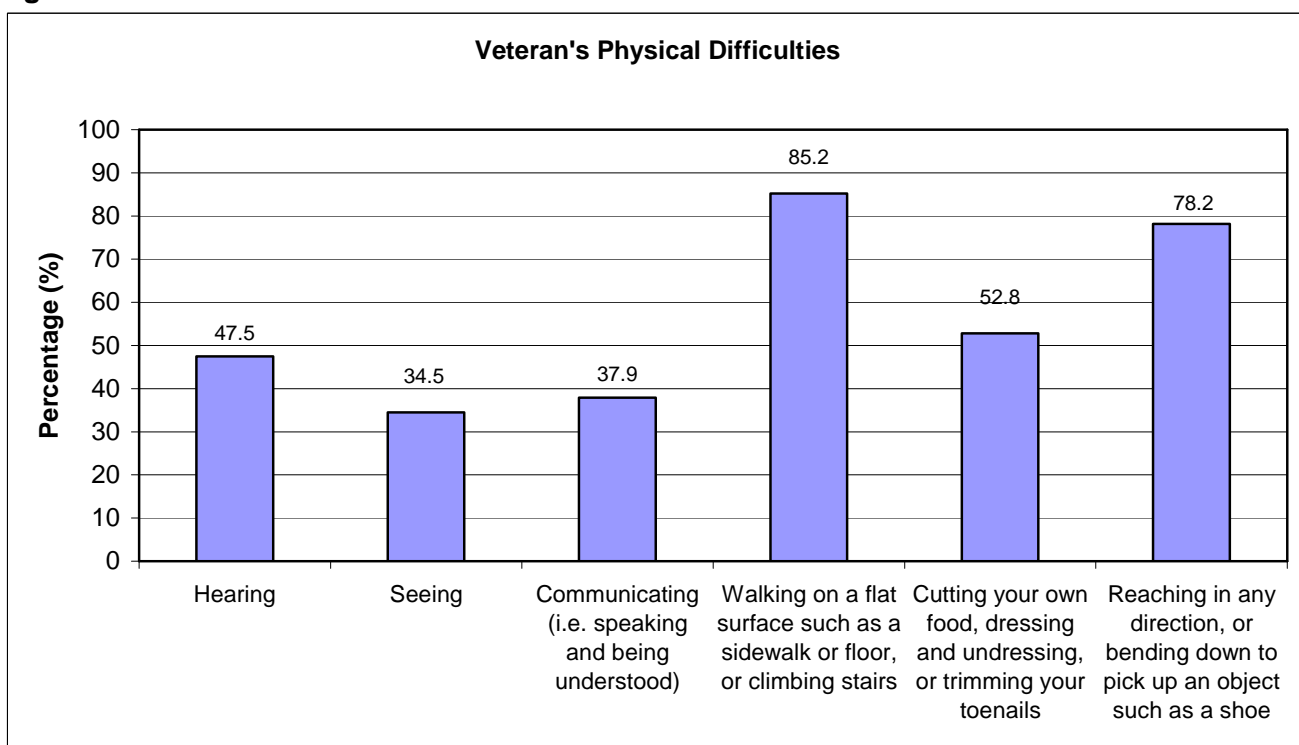


Figure 2



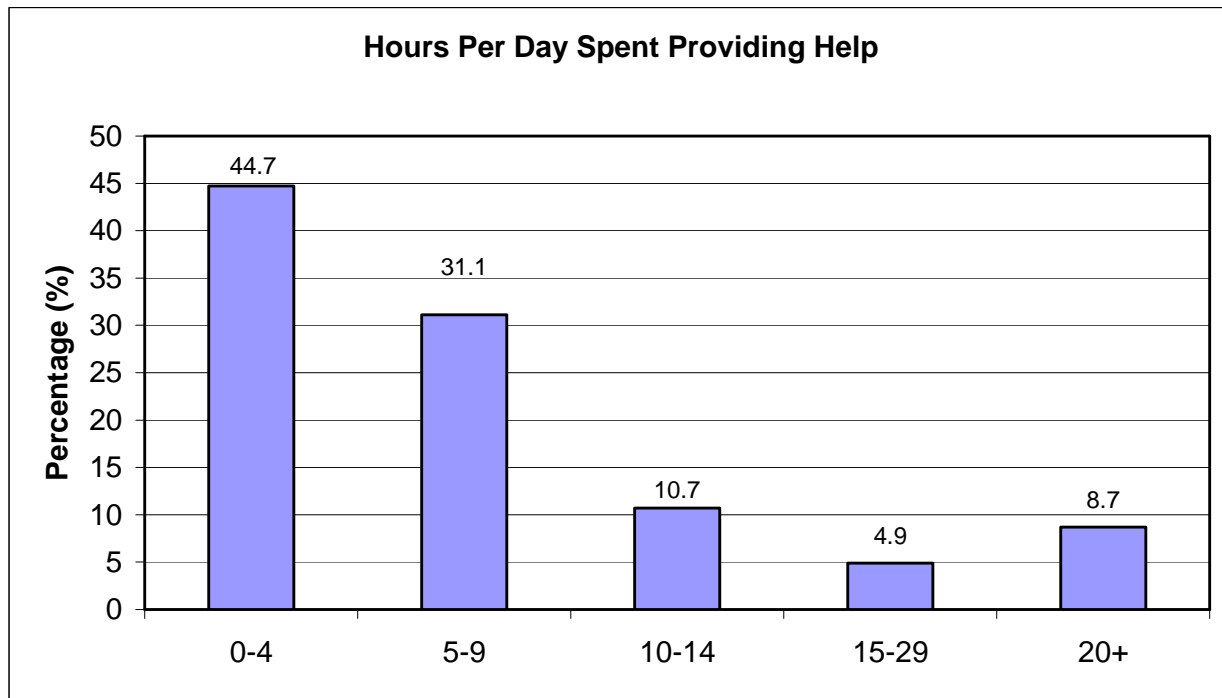
Supporters to Veterans with disabilities

Veterans Affairs Canada sent letters to Veterans with background information about the survey. If the Veteran agreed to participate in the survey they then provided their name and the name of their main

caregiver. Both the Veteran and the caregiver¹ filled in and mailed the consent forms to the university (HCIC) research team. Most (94%) identified their spouse as their main supporter², though sisters and brothers (2%), other relatives (1%), friends (2%) and others (2%) also were named. We did not speak directly to family members in addition to these 'main supporters' who also might have been helping, though our previous research suggests that there may be more than one person. Thus we do not know about the roles in or consequences of supporting the Veteran for anyone other than the main supporter. However, we do get glimpses of the impact on these other family members from spouses' comments.

Supporting a Veteran with high levels of disability is a long term process. Almost 40% of spouses had been providing support for between 10 and 19 years. Another 24% had been providing this care for more than 20 years. Further, almost 40% reported that the time they spend helping had increased over the years. They were investing many hours in these helping tasks: 55% reported spending 5 or more hours *every day* helping the Veteran (Figure 3). In a parallel study of main supporters to persons with disability not affiliated with Veterans Affairs Canada, approximately 28% of caregivers reported helping their care receiver 5 hours or more per day. Clearly veterans in this study had very high needs arising from their disabilities. However, impact on their caregivers also is relatively severe even when compared to those providing end-of-life care, another group of high-impact caregivers. In our previous research, we found that the latter group provides an average of 10 hours per week of care (Fast, et al., 2002a, 2002b).

Figure 3

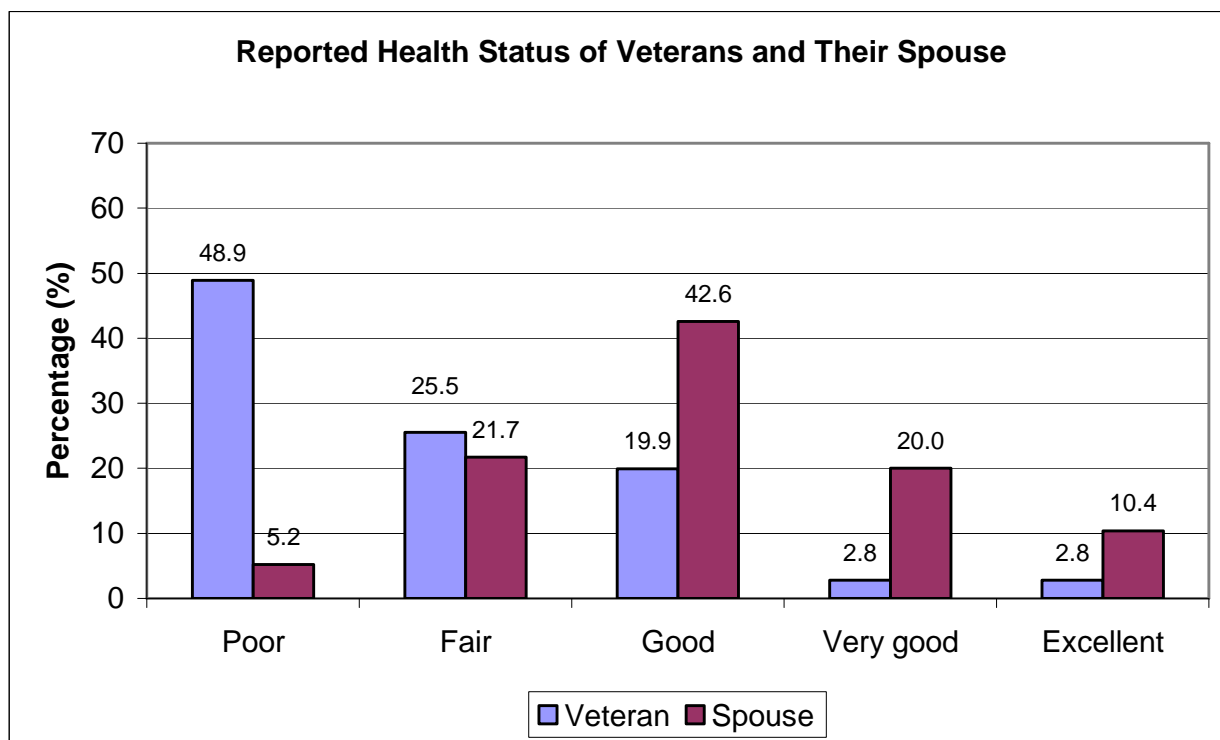


The burden of providing care is evident in the spouses' reports on their own health; 27% reported that their health was fair or poor, while approximately 10% reported excellent health (Figure 4).

¹ The term 'main supporter' was used in our interactions with veterans and the person that they indicated was their major supporter. In the report we use the term caregiver which is consistent with general definitions of care being assistance provided because of the recipient's long term health problem or disability.

² Since most main supporters are spouses, we use the term spouse for the remainder of this report.

Figure 4



Economic consequences: “The financial cost alone is tremendous”

Like the disabilities of the Veteran, care is chronic. Lives are changed as a result of providing such high levels of support over many years. Families experienced high levels of economic and non-economic consequences as a result of the disabilities of the Veterans and the support they provided.

Spouses experienced considerable impact on their employment as a result of providing high levels of support over the long term. Employment impacts are important because they affect the short and long term economic situation of the family. In the short term, families’ income and benefits may be reduced. In the long term, retirement pensions and benefits, as well as ability to save for retirement, are compromised. Figures 5 and 6 show effects of care responsibilities on employment.

As Figure 5 illustrates, large proportions of spouses experienced disruptions in their employment. Between 40% and 50% missed work, came late or left early, or rescheduled work in some way. Since they started caring for the Veteran, almost half had decided not to apply for a job, limiting their opportunities for advancement. These figures are much higher than among the general population of caregivers. In 1996 between 3% and 34% of those providing chronic care, and between 21% and 45% of those providing end-of-life care, reported similar types of employment consequences (Fast, *et al.*, 2002a, 2002b). In 2002 the rates reported by eldercare providers age 45 and over were between 3% and 22% (Walker, 2005). Some respondents, when given the opportunity to further comment or expand on their survey responses, volunteered examples of how their support to the Veteran had impacted their employment.

“They won't pay someone to look after him so I've lost at least \$25,000 a year by taking a half time job so I could look after him.”

“The hidden cost to me was the loss of my job.”

Figure 5

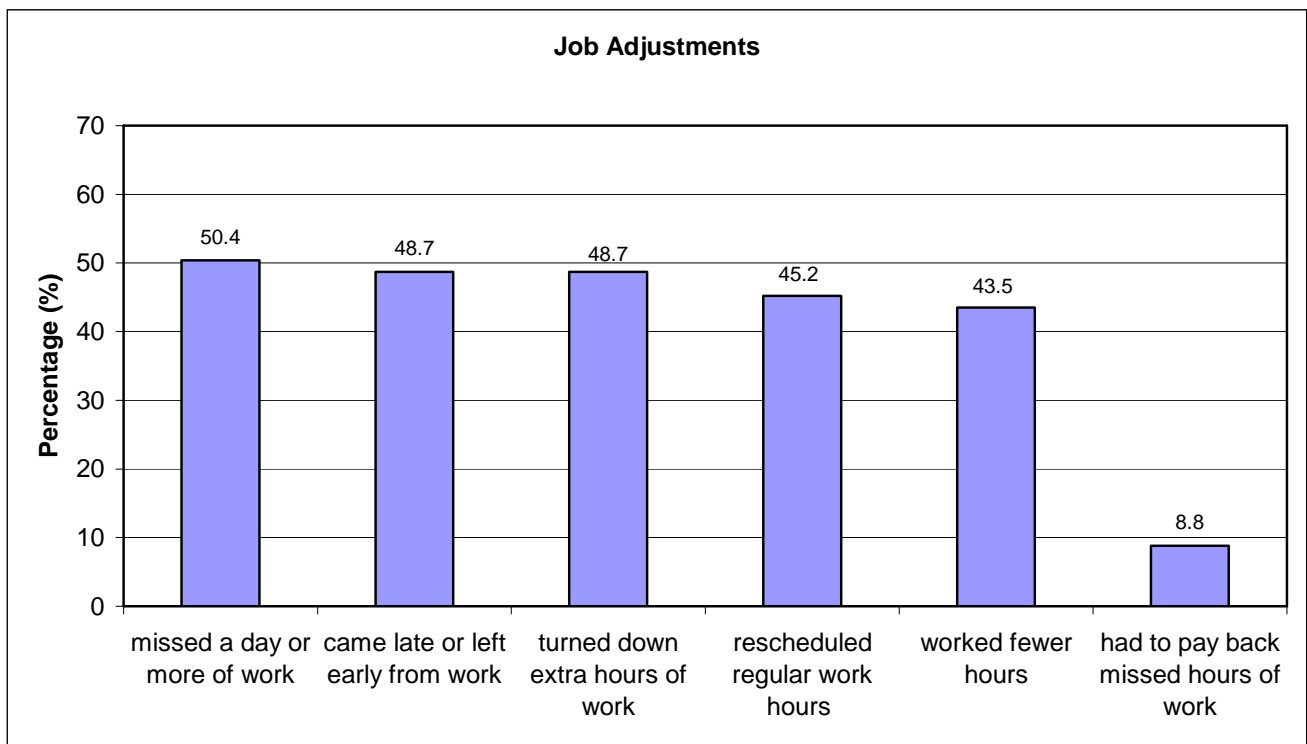
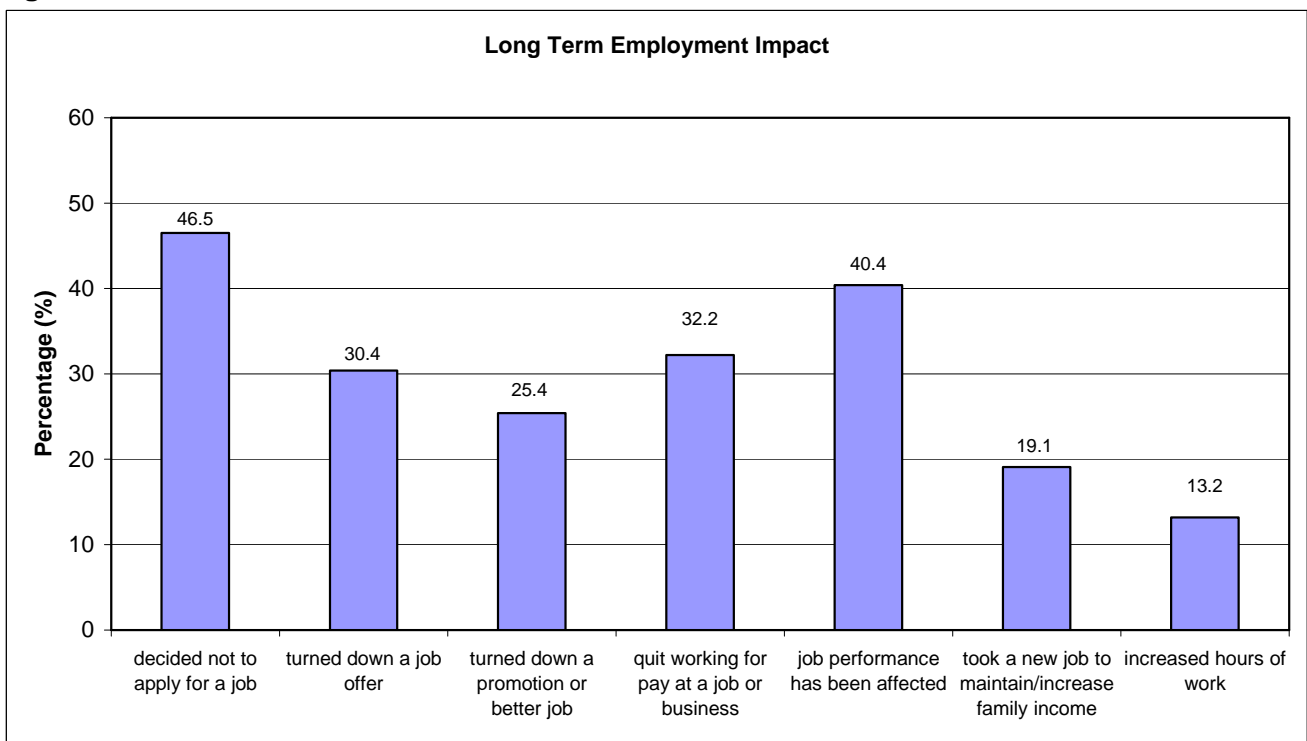


Figure 6



Longer term employment decisions often translate into reduced income security for families. Many spouses had decided not to apply for a new job or had turned down job offers or promotions (Figure 6). Some had taken on new jobs or increased their hours of work to compensate for lost income or increased expenses related to caring of the Veteran. As one wife said:

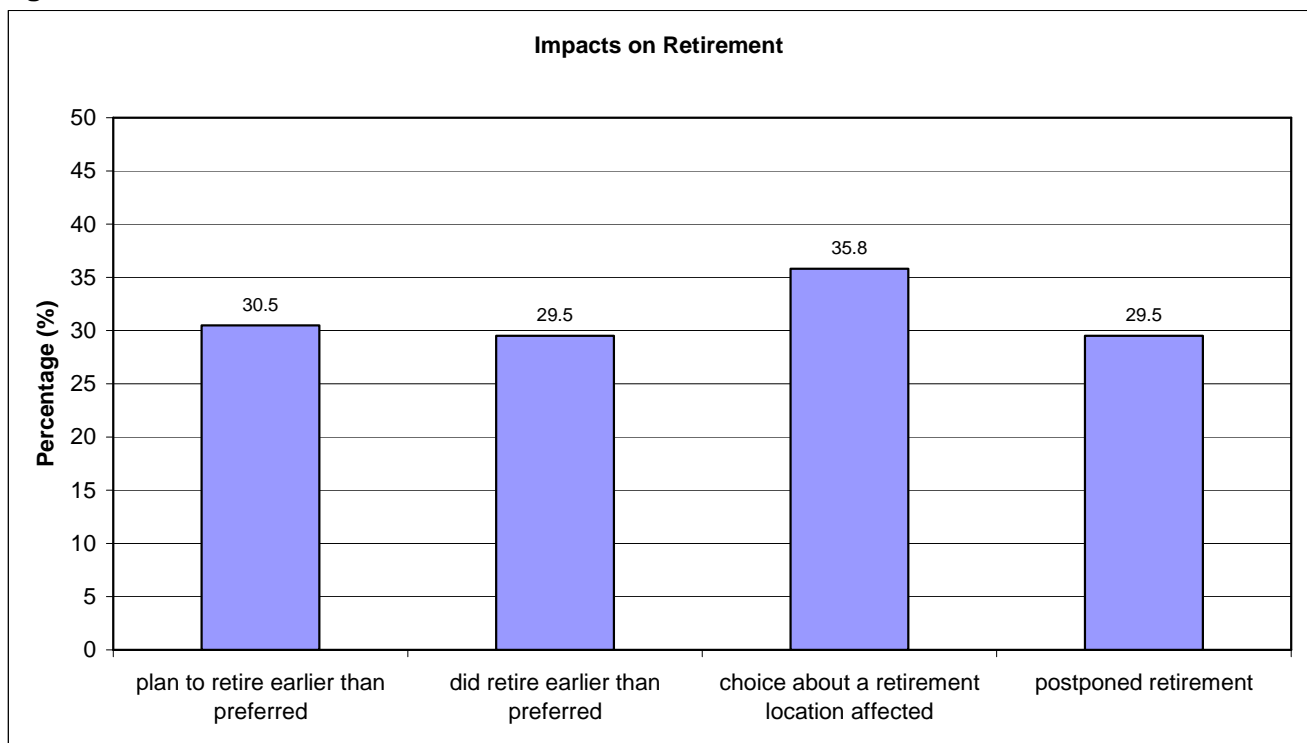
“I wish there were more opportunities for me to stay home and help.”

Many also changed their retirement plans (Figure 7). Almost 60% expected to retire earlier than they had previously planned, or actually had retired early, in order to provide the care their Veteran spouse needed. Another 30% stayed longer in the labour force than anticipated to offset losses or extra expenses. Even the choice of retirement location had been impacted by their situation. A couple of spouses commented on their disappointments in retirement:

“I tend to try to be positive not negative, I think of how his accident happened. I feel robbed because all our lives he has been ill, can't sit, walk, or stand too long. We can't do things in our retirement.”

“What frustrates me is that in retirement I'd like to do things and travel and do what other people do, and we can't. It's frustrating that we're going to sit around and exist in our house.”

Figure 7



For some, there were dramatic changes in their families' financial situation as a result of supporting the Veteran (Figure 8). The cumulative effect of lost wages and benefits and extra expenses is profound: approximately 43% of spouses said they were earning less money and experiencing financial hardship (41%); and almost as many (35%) are concerned about being able to provide adequately for their families' financial futures. One spouse reported an especially startling financial sacrifice:

“Our income is dramatically reduced: I would be making \$100,000 at the job lost due to it. His disability lump sum is no where near the salary he would have had, and he's lost the opportunity for another salary after military retirement.”

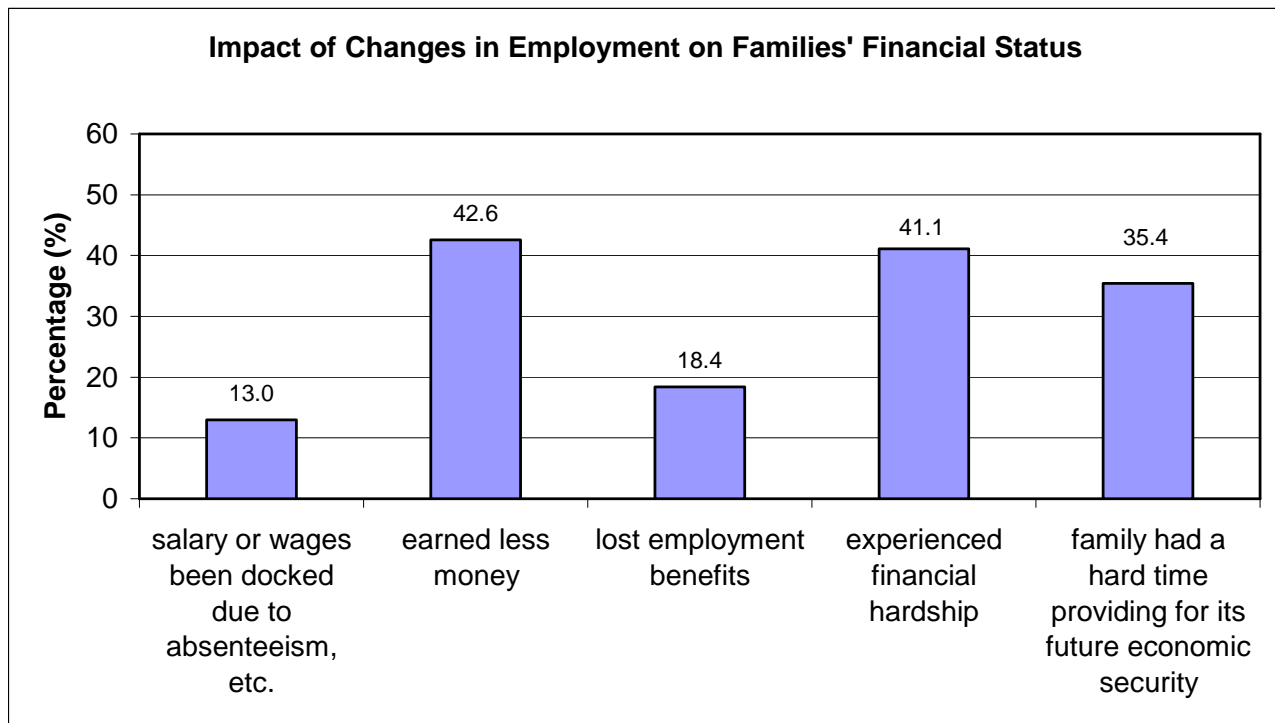
Spouses may be torn between the need to work and to care for their families:

“The biggest problem is the... loyalties divided between caring for your family and bringing in a wage. Who suffers the most? The kids suffered.”

“When I worked there were more problems in the family unit.”

In addition to long term financial losses because of employment, approximately 60% of supporters reported that they also incurred extra expenses for the Veteran—mainly for his medications, and for travel or transportation. For many, these out-of-pocket expenditures were modest, but for 16% they exceeded \$5,000 in the past year. These findings foreshadow the potential for lifelong economic costs related to the service experience of families of a Veteran with service related disabilities.

Figure 8



Health and social consequences: “The non-financial cost, you can't count it”

The health and social consequences resulting from supporting the Veteran were equally common and worrisome. They often are less tangible than economic costs, but have a powerful impact on supporters and their families:

“Everything is affected because I have to do things for him that he can't do for himself, so everything that I would do otherwise is decreased. It is more draining on emotions than the physical. The financial cost alone is tremendous, the non-financial cost, you can't count it.”

As shown in Figure 9, the majority were exhausted, did not get enough sleep, and lacked time for any personal activities. Not surprisingly, most also said that their health was affected.

“I'm sure that it's because of my situation that I'm clinically depressed.”

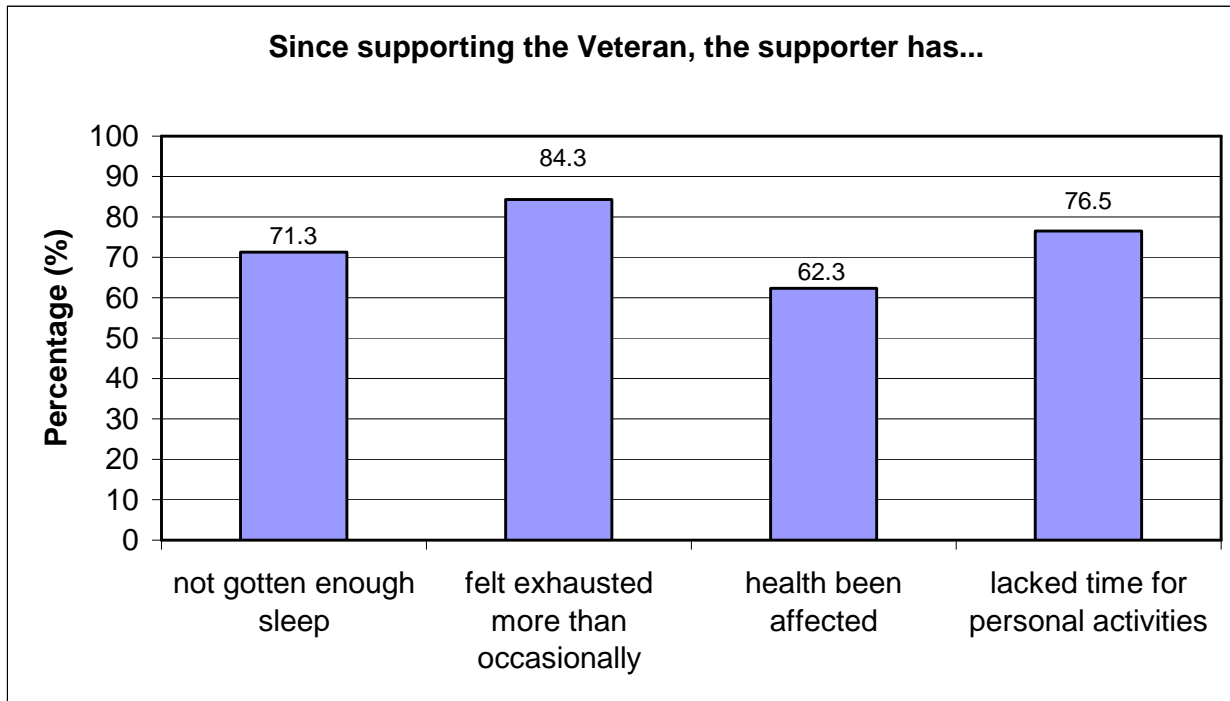
“About the stress question, I can't answer it in general because there is no predicting. Sometimes it is good, sometimes it is bad, you never know when.”

Mental health problems of the Veterans are especially difficult for their wives to deal with.

“Because his illness is mental it is difficult for people to completely understand and you almost think things are ok, but there are lingering things. He's doing better, but the little things that are there forever finally eat away and it hits you all at once.”

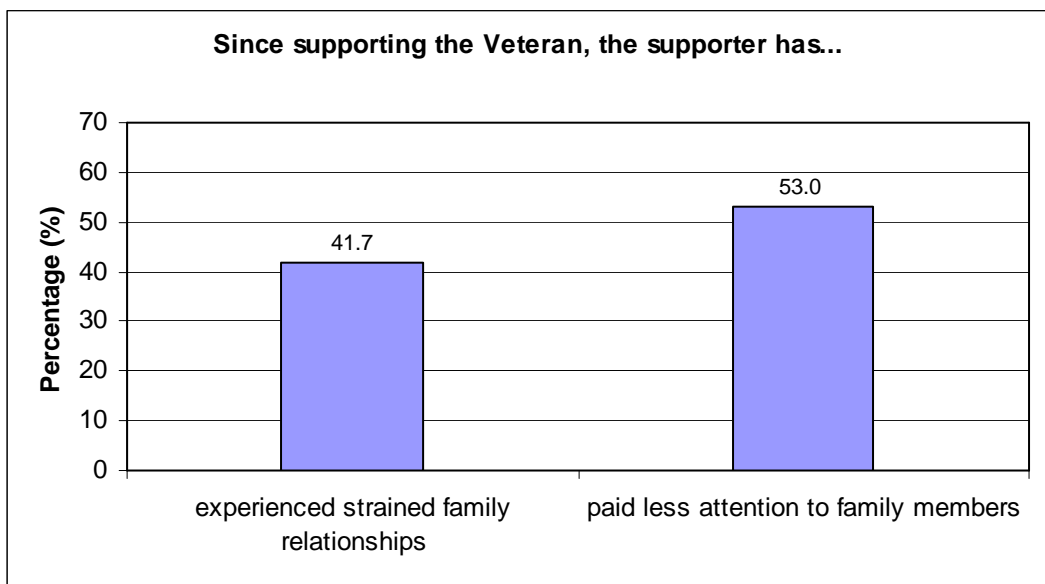
“I would say in our case my husband suffers from PTSD [post traumatic stress disorder] which is a predominantly mental health issue and so we don't deal with the physical aspects but we deal with the psychological aspects *ALL THE TIME.*”

Figure 9



Families suffer as a result of such strain. As shown in Figure 10, 53% said that they paid less attention to their other family members as a result of their caregiving, and that family relationships had been strained. There also are indications of potential isolation of these families.

Figure 10

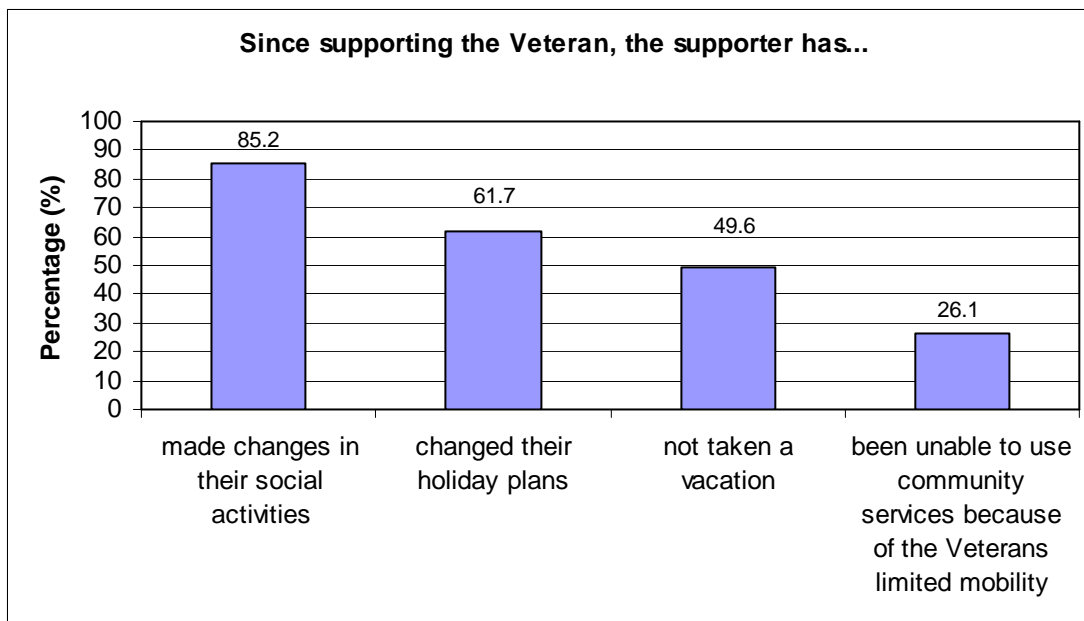


Most made changes in their social activities, changed their holiday plans or took no vacation (Figure 11). Chronic disabilities often make vacations impossible. Interviewers recorded the following comments from wives who had been supporting their husbands for many years.

“[She] took a three day holiday to check out a retirement home, which is why she said she went on a holiday. No other holiday was taken last year.”

“She wishes they could still go to Alaska, but the answer is no as it's not practical, no physically demanding activities are done. She goes swimming as [her husband] watches. She has at times felt resentful because of the changes to her life as she chooses to do things with [her husband]. She said she doesn't want to go on vacation alone.”

Figure 11



Comments from supporters underscore the enormity of the task that they have taken on:

“It makes you...it opens your eyes again. You don't dwell on it, you shut them and try to think of something good every day; you just try to keep going. A few years ago I had to write a letter to Veterans Affairs and I thought "Oh my God, this is my life." It was so depressing for a few days.”

“It's interesting how it affects the caregiver...I thought it was work, and wore blinders. Now I realize the effects. When I did go on stress leave and talked to close friends, they said 'I don't know how you dealt with it.’”

The cumulative effect of all of the strains is immense. For these families, life is forever changed.

“I think that there may not be any way of capturing the ten year period of adjustment...”

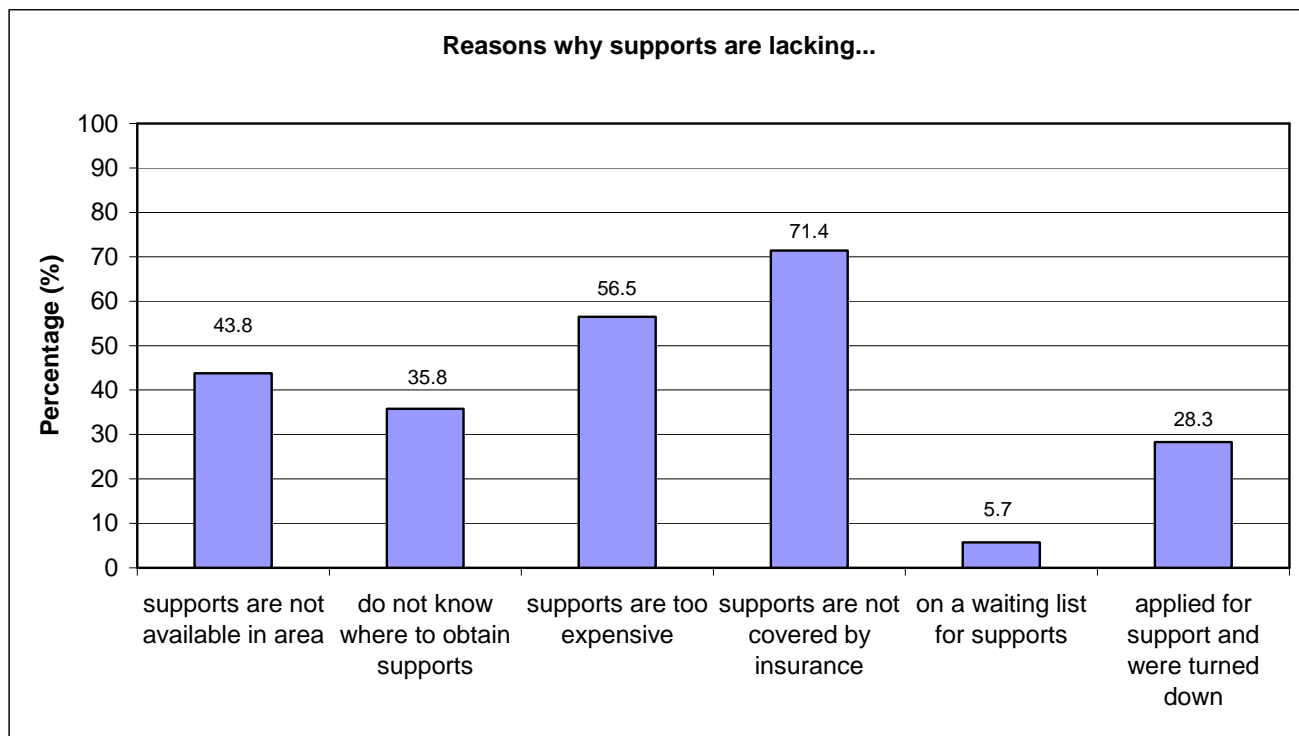
“In the beginning I felt I was dealing with it well quite well. As time went it has eaten away at me, this crept up quite quickly. Last year things that didn't bother me before were bothering me so much that I took nine weeks of stress leave. I was able to reconnect with him. If you don't take the time you reach rock bottom. Then you say I've been dealing with it for 10 years and have been able to cope. When you hit rock bottom you realize you do have a breaking point.”

Services: “It doesn't reveal struggles for support”

Services from the public or non-profit sector can help off-set the stresses of supporting someone with a serious disability. In fact, VAC has services for veteran clients not available to non-veterans with disabilities. In this study, we did not ask participants whether they were accessing any of these programs. Nonetheless, we found that almost half (48%) of the supporters of these Veterans with high levels of disability reported needing assistance that they did not have. Approximately 67% said they lacked the help they needed to continue to care for the Veteran, an indication of the fragility of such families. As one wife said:

“It was a very bitter struggle for ten years with Veterans Affairs to get a pension...we're always under threat of losing it. Where's the compassion? All he has is medication, a bed, a walk once a day. He panics if I am not in the room.”

Figure 12



Chief among the reasons for lacking needed supports is cost. More than half (57%) said that supports were too expensive and/or not covered by insurance (Figure 12). Smaller proportions said that supports were not available in their area (43.8%) or that they did not know where to obtain assistance (35.8%). A minority (28.3%) had applied for supports but had been turned down. In all, resources of these families were being stretched with little other assistance available.

The voices of supporters/family members show the strain of the ongoing challenge of getting support:

“Every penny from Veteran Affairs you have to fight for, appeal - a councilor told us that. We've appealed six times now, reliving every detail, dwelling on it all... on the pain -- he won't anymore -- it's too much for him. It's such a strong emotional cost.”

“The card that he has is supposed to be cleared with everything but it's not. If I go to get a cane, exercise ball, or patches for his exercise machine... we went to get his cane 3 weeks ago and it still hasn't been cleared. We had to fight for his massage, everything, for his quality of life. You have to fight for everything you get from DVA.”

“[It would help to have an] increase in financial aid without [the] distress of asking for it. They are making us feel like beggars who are bothering them. Not all of us are taking advantage of the system.”

“Independence program needs to be increased automatically every year or so, to know that it is being considered and that they are a concern and being taking care of without asking for it.”

“Too much stress filling in receipts, sending them out.”

“Too much unnecessary paperwork. If you don’t get the paper work done by certain deadlines then no reimbursement.”

“Adding stress to an already stressful situation. Don’t make us fill out forms for financial increase that they know we need.”

“It would be great to have an on-line support group, even to talk to. There is a group in [the city], but it is a three hour drive one way.”

VAC services were seen as generous in many ways. However, the inflexibility of services meant that needs often were not met. Services need to be timely and appropriate to the particular needs of the Veteran and caregiver:

“It seems quite comprehensive. It is difficult to hit anyone right on, but in my case it seems to cover everything that concerns me.”

“When he was first diagnosed there was no support for anyone, but now there is.”

“They [VAC] have some very weird things going. We qualify for help cleaning the house, or yard, but they refused somebody to clean our blinds. The really difficult things, taking the blinds down and washing them, I can't get any help with. It is always the little things like that.”

“Because of long term notice we're not able to utilize the services because to send him somewhere for a week you need to give I think a months notice. I don't know beforehand from week to week whether he'll be well enough. Income does come into it but the other supports are even more important.”

“Supports that he needed were turned down by the VA. He has a huge problem with hearing and it affects his everyday life. He needed a device to speak on the phone and he was turned down, so now he never picks up the phone. The hearing problem has also led to depression and affects everyday life and keeps him isolated.”

“She had said that some of the supports they wanted the VA are odd about them. They wanted to get an electronic bed and they said no but they gave him a hospital just for him. So they asked if the money that they spend on the hospital could be given to them and they could pay for the bed they want. The VA turned them down. Also they need more money for cleaning the snow because he cannot do it and she works, but again they said they cannot be given more money for that assistance.”

“VA gives you a pension and they just want you to shut up and go away. They aren't involved, we don't hear from them.”

“They wanted a lift put on the truck; we wanted to use ramps like a SUV. They said no, if you get it you have to do it this way, have to do it this route.”

“Two hours are paid each day. She could honestly use 3 hours of help, those 2 hours take in personal care and housekeeping. It is not enough time.”

Support from Veterans Affairs: “they don't include the family”

This study did not include questions about impact on families nor about support to them to assist with managing changes in their lives. Yet comments indicate that some caregivers felt that they and their families were invisible:

“Health benefits offered through Veteran's Affairs sometimes include the family but in [his] case they don't include the family. He can't get health insurance because of his condition and Veteran's Affairs only covers his condition when he left the forces. I work part time so I don't have any health benefits so it's frustrating.”

“I have had zero support myself. Nor have I ever been contacted about supports outside this survey. It seems like the care supporter doesn't matter at all. I would like to see ways to get support made easier.”

“I would appreciate easier access to either somebody to come into our house or maybe sending him to the Veteran's home so I can get away with my family or so we can have a break from each other.”

They worried not only about their ability to sustain support to the Veteran, but about the impact of long term disabilities on the rest of the family:

“What I want to know, and I have asked this before, is there ever going to be any help for the children? They have help for the spouses, the wives, but will there be help for the children? Counseling for the children from someone who knows about PTSD.”

“About other costs or services for the family, can you say that my daughter's depression and medication is due to his condition, or is she just a depressed teen.”

“The psychological help that is needed is not provided or available for her adult sons. Her sons are 30 and they have a hard time dealing, and when the help is provided to the father or her but not them because they are not covered by the VA, that simply is not good since the whole family is hurt by his situation.”

Young people in an old culture: “we seem to be the only young ones around”

Supporters also noted the difficulties of being young Veterans with high levels of disability. They did not expect to be dealing with problems that they associated with later life. They felt that groups like the Legion and VAC were geared to traditional Veterans.

“The biggest reason that I did do this survey is that I don't think that there are that many of us who are young, and we aren't used to, don't know how to deal with VA. Most vets are over 65. We have no support group to talk to; we're dealing with different issues. It's tough on young kids because they see everyone else's dad playing baseball, and they don't understand. You feel alone a lot. We seem to be the only young ones around... going to the Legion we get looked at as why are you here.”

“We're a young Veteran; we're just trying to figure out all those things. You expect these things of the old Veterans, not 40 year olds. There are no supports for young Veterans here.”

“The disability that creates a barrier with social activities is his blindness and seizures. The Royal Canadian Legions asked him not to come back because he had seizures, before that no one would play cards with him anyways. The age barrier exists for [him]

because of his disability and the social supports available. He didn't want to be with men so much older and this left him feeling alone, if he did try to participate.”

Next steps: Responding to the needs of families of Veterans

Findings from this study tell us that supporters to adults with severe, long-standing and complex disabilities are far more likely than the general population of caregivers to have reported almost every one of the major categories of economic and non-economic consequences of care. High proportions of supporters reported financial insecurity, stressful lives and low levels of life satisfaction. They worry about their ability to sustain care for the Veteran. They worry about their families whose lives had been changed profoundly.

The strongest message in these findings is that families have suffered as a result of the service-related disabilities of the Veteran. For this new generation, the VAC mission of providing exemplary service to Veterans *and their families* has never been more important.

There are two sets of recommendations that flow from this key message:

1. Approaches and principles in providing services to families of veterans with high levels of disabilities.
 - a. Entitling families. Families have suffered as a result of service-related injuries of their Veteran family member. ‘Wounded families’ should be entitled to compensation just as are ‘Wounded Veterans’. Yet, many services to families of Veteran clients are derivative services; that is, families may derive benefits indirectly as a result of services provided to the Veteran. Because they are indirect, such approaches to serving families can be cumbersome and are not consistent with principles of entitlement. The department may wish to consider how to move quickly to support families given current program delivery and eligibility constraints; while working toward the goal of increasing direct entitlement of families.
 - b. Focusing on needs. High levels of economic, social and health needs of family members were evident in this study. A focus on needs of families would allow for specific targeting of services to families experiencing high needs flowing from the service-related injury/disability of the Veteran. Needs assessment protocols for main supporters and other key family members will be necessary to implement a needs-based approach to supporting families.
 - c. Beginning with spouses and children. In this study, spouses were the largest group of supporters. Their ability to be in the labour force, to stay connected to their own support networks, retain their health, and support their children, are critical to the stability of their families and to the care of the Veteran. We did not hear the voices of children of Veterans. However, reports from main caregivers suggest that their needs have been rendered invisible.
 - d. Using a ‘needs-based’ family lens to guide the implementation of the New Veterans Charter. In the last few years, the department has made great strides in updating and rethinking services for families of traditional Veterans. In the process of this realignment of services, VAC has moved toward a ‘needs-based’ philosophy of services. Such an approach, coupled with a view of families as entitled to services, will help alleviate the negative consequences experienced by families of Veterans of all ages who have high levels of disability.
2. Areas of greatest support needs of families.
 - a. Economic needs. Employment impacts on spouses (and other main supporters) are high. Main supporters need assistance with maintaining or increasing their labour force engagement in order to support their families. Strategies to support labour force engagement might be direct (such as retraining or employment counseling) and indirect

- (such as providing caregiving assistance to free the main supporter to engage in the labour force). Since care is long-term, attention needs to be paid to strategies to assist families in developing adequate pension coverage to reduce their long-term employment-related economic costs.
- b. Health needs. Main supporters experience high levels of physical and mental health problems as a result of their high levels of caregiving over long periods of time and of their distress related to the acquired disabilities of a family member. Strategies need to be developed to provide spouses with long term relief from caregiving, tailored to their needs. Mental health needs of caregivers and their children must be addressed directly (such as through access to family therapists, and other skilled family supports) and indirectly through health promotion (such as work with school counselors to increase their understanding of the needs of children of Veterans with acquired disabilities).
 - c. Social needs. Families are at risk of isolation and burn out because Veterans' disabilities and care needs may preclude vacations or recreation, and make social contact difficult. Concerted effort to assist families in developing new strategies for social connections may reduce long term mental health problems of spouses and children. The department also might work with Veterans organizations to develop strategies to maximize their ability to be inclusive to younger Veterans with high levels of disabilities.
 - d. Access to services. High levels of distress about service availability and access were evident among caregivers. It would be useful for the department to undertake an evaluation of how current and newly developed programs and services might best meet the needs of Veteran clients with high levels of disabilities and the needs of their families.

This report provides evidence of the special needs of families of younger Veterans. We provide it in the interest of assisting the department with their process of providing the best possible services to the families of Veterans of all ages.

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APPENDIX A

| | | VAC Sample Frame (N= 1059) | | VAC Sub-Sample Characteristics (N=158) | |
|---------------------------------------|------------------------------------|----------------------------------|------|---|------|
| | | N | % | N | % |
| Province | AB | 166 | 15.7 | 21 | 13.3 |
| | BC | 125 | 11.8 | 11 | 7.0 |
| | MB | 36 | 3.4 | 6 | 3.8 |
| | NB | 80 | 7.6 | 19 | 12.0 |
| | NL | 49 | 4.6 | 12 | 7.6 |
| | NS | 123 | 11.6 | 23 | 14.6 |
| | ON | 251 | 23.7 | 37 | 23.4 |
| | PE | 9 | 0.8 | 2 | 1.3 |
| | QC | 206 | 19.5 | 26 | 16.5 |
| | SK | 13 | 1.2 | 1 | 0.6 |
| | YT | 1 | 0.1 | 0 | 0 |
| Marital Status | Common-law | 165 | 15.6 | 22 | 13.9 |
| | Divorced | 13 | 1.2 | 1 | 0.6 |
| | Married | 682 | 64.4 | 112 | 70.9 |
| | Separated | 48 | 4.6 | 4 | 2.5 |
| | Single | 146 | 13.8 | 17 | 10.8 |
| | Widowed | 5 | 0.5 | 2 | 1.3 |
| Gender | Female | 81 | 7.6 | 12 | 7.6 |
| | Male | 968 | 91.4 | 144 | 91.1 |
| | Unknown | 10 | 0.9 | 2 | 1.3 |
| Age Groups | 25-34 | 33 | 3.1 | 2 | 1.3 |
| | 35-44 | 354 | 33.5 | 46 | 29.1 |
| | 45-54 | 396 | 37.5 | 57 | 36.1 |
| | 55-64 | 266 | 25.2 | 51 | 32.3 |
| | 65+ | 7 | 0.7 | 2 | 1.3 |
| Assessment Level of Disability | Class 1 (98% and over) | 428 | 40.4 | 68 | 43.0 |
| | Class 2 (93 - 97%) | 75 | 7.1 | 9 | 5.7 |
| | Class 3 (88 - 92%) | 153 | 14.4 | 21 | 13.3 |
| | Class 4 (83 - 87%) | 161 | 15.2 | 25 | 15.8 |
| | Class 5 (78 - 82%) | 242 | 22.9 | 35 | 22.2 |
| Number of Conditions | 1 | 47 | 4.4 | 2 | 1.3 |
| | 2 | 116 | 11.0 | 17 | 10.8 |
| | 3 | 149 | 14.1 | 23 | 14.6 |
| | 4 | 191 | 18.0 | 28 | 17.7 |
| | 5+ | 556 | 52.5 | 88 | 55.7 |
| Most Frequent Conditions | Psychiatric Conditions | 675 | 63.7 | 91 | 57.6 |
| | Musculoskeletal | 603 | 56.9 | 96 | 60.8 |
| | Disc Disease and Spinal Conditions | 534 | 50.4 | 83 | 52.5 |
| | Nervous System | 441 | 41.6 | 72 | 45.6 |
| | Ear | 275 | 26.0 | 39 | 24.7 |
| | Accidents/External Violence | 261 | 24.6 | 47 | 29.7 |