**Caregiver ID: \_\_\_\_\_\_\_\_\_\_\_**

**PLEASE COMPLETE TODAY AND RETURN TO THE FRONT DESK**

Please contact the research team with any questions:

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**Date: \_\_\_\_\_/\_\_\_\_\_\_/\_\_\_\_\_\_**

**Caregiver Intervention Study**

**DFCI Protocol 18-426**

*PI: Deborah A. Forst, MD*

Answer each question by checking the case that comes closest to what you thought or felt **during the last four weeks.**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| During the last four weeks, in connection with the person you help, have you… | Never  Not at all | | Rarely  A little | Sometimes  Moderately | | | | Often  A lot | | | Always  Enormously | | |
| 1. Been worried, anxious? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been sad, depressed? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been emotionally tired, worn out? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been stressed? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Felt a lack of freedom? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been bothered by the feeling of being confined? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been bothered by the fact that your life was entirely devoted to the care recipient? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been embarrassed to be the only person to provide assistance? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been satisfied with information given by health care providers (doctors, nurses …)? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Been reassured by the health care providers (doctors, nurses …)? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Felt that your role as caregiver was recognized by health care providers (doctors, nurses …)? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Had financial difficulties (lodging, transportation …)? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| 1. Had other difficulties (lodging, transportation …)? | | 1 | | 2 | | 3 | | 4 | | | 5 | | |
| **During the last four weeks, in connection with the person you help, have you…** | | | **Never**  **Not at all** | | **Rarely**  **A little** | | **Sometimes**  **Moderately** | | | **Often**  **A lot** | | | **Always**  **Enormously** |
| 1. Encountered difficulties in the administrative process (health insurance paperwork and other paperwork related to the cancer illness)? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Experienced feelings of guilt? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Been bothered by a feeling of helplessness against disease? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Felt a feeling of injustice, anger, or rebellion? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Had sleeping difficulties? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Had problems with your appetite? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Been physically tired, worn out? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Had the impression that your health was fragile? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Felt you made a difference for the person you are helping? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Felt useful? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Could rest, relax? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Could take care of yourself, pay attention to your own health? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Been assisted, supported, understood by your family? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Been assisted, supported, understood by your friends? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Had difficulties in your intimate, emotional life? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |
| 1. Had a satisfying love and sexual life? | | | 1 | | 2 | | 3 | | | 4 | | | 5 |

**Read each item and please select the answer which comes closest to how you have been feeling, on the average, IN THE PAST WEEK**

1. I feel tense or "wound up."

1. Most of the time
2. A lot of the time
3. From time to time, occasionally
4. Not at all

3. I get a sort of frightened feeling as if

something awful is about to happen.

1. Very definitely and quite badly
2. Yes, but not too badly
3. A little, but it doesn't worry me
4. Not at all

5. Worrying thoughts go through my mind.

1. A great deal of the time
2. A lot of the time
3. From time to time but not too often
4. Only occasionally

7. I can sit at ease and feel relaxed.

1. Definitely
2. Usually
3. Not often
4. Not at all

9. I get a sort of frightened feeling like "butterflies" in the stomach.

1. Not at all
2. Occasionally
3. Quite often
4. Very often

11. I feel restless as if I have to be on the move.

1. Very much indeed
2. Quite a lot
3. Not very much
4. Not at all

13. I get sudden feelings of panic.

1. Very often indeed
2. Quite often
3. Not very often
4. Not at all

2. I still enjoy the things I used to enjoy.

1. Definitely as much
2. Not quite as much
3. Only a little
4. Hardly at all

4. I can laugh and see the funny side of things.

1. As much as I always could
2. Not quite so much now
3. Definitely not so much now
4. Not at all

6. I feel cheerful.

1. Not at all
2. Not often
3. Sometimes
4. Most of the time

8. I feel as if I am slowed down.

1. Nearly all the time
2. Very often
3. Sometimes
4. Not at all

10. I have lost interest in my appearance.

1. Definitely
2. I don't take so much care as I should
3. I may not take quite as much care
4. I take just as much care as ever

12. I look forward with enjoyment to things.

1. As much as I ever did
2. Rather less than I used to
3. Definitely less than I used to
4. Hardly at all

14. I can enjoy a good book or radio or TV program.

1. Often
2. Sometimes
3. Not often

d. Very seldom

Please answer the following items with regards to caring for your loved one during their illness.

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | | Strongly agree | | Agree | | Neither agree or disagree | | Disagree | | Strongly disagree | |
| I feel privileged to care for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| Others have dumped caring for my loved one onto me | | 1 | | 2 | | 3 | | 4 | | 5 | |
| My financial resources are adequate to pay for things that are required for caregiving | | 1 | | 2 | | 3 | | 4 | | 5 | |
| My activities are centered around care for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| Since caring for my loved one, it seems like I am tired all the time | | 1 | | 2 | | 3 | | 4 | | 5 | |
| It is very difficult to get help from my family in taking care of my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I resent having to take care of my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I have to stop in the middle of work | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I really want to care for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| My health has gotten worse since I have been caring for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I visit family and friends less since I have been caring for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I will never be able to do enough caregiving to repay my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| My family works together at caring for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I have eliminated things from my schedule since caring for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| I have enough physical strength to care for my loved one | | 1 | | 2 | | 3 | | 4 | | 5 | |
| Since caring for my loved one, I feel my family has abandoned me | | 1 | | 2 | | 3 | | 4 | | 5 | |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | | Strongly agree | Agree | Neither agree or disagree | Disagree | Strongly disagree |
| Caring for my loved one makes me feel good | | 1 | 1 | 2 | 3 | 4 | 5 |
| The constant interruptions make it difficult to find time for relaxation | | 1 | 1 | 2 | 3 | 4 | 5 |
| I am healthy enough to care for my loved one | | 1 | 1 | 2 | 3 | 4 | 5 |
| Caring for my loved one is important to me | | 1 | 1 | 2 | 3 | 4 | 5 |
| Caring for my loved one has put a financial strain on the family | | 1 | 1 | 2 | 3 | 4 | 5 |
| My family (brothers, sisters, children) left me alone to care for my loved one | | 1 | 1 | 2 | 3 | 4 | 5 |
| I enjoy caring for my loved one | | 1 | 1 | 2 | 3 | 4 | 5 |
| It is difficult to pay for my loved one’s health needs and services | | 1 | 1 | 2 | 3 | 4 | 5 |

We would like to know how confident or sure you feel about some of these areas that arise when you are going through **the experience of caring for a loved one with cancer**. Please rate your degree of confidence for each sentence by circling a number from 0 to 10 using the scale shown. When you choose a higher number, you are telling us you are more confident.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Rate the confidence you feel TODAY |  | Not at all  confident | | | | | | Very  confident | | | | | | |
| 1. I am confident that I can use information and resources to cope with the demands of my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 2. I am confident that I can call on my inner strengths to pull myself through my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 3. I am confident that I have what it takes to help my family through this illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 4. I am confident that I can maintain close communication with my loved one about their illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 5. I am confident that I can take the necessary steps to work through the demands of my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Rate the confidence you feel TODAY |  | Not at all  confident | | | | | | Very  confident | | | | | | |
| 6. I am confident that I have what it takes to help my family handle this illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 7. I am confident that I can handle the challenges of my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 8. I am confident that I have ways to manage the uncertainty brought on by my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 9. I am confident that I can manage difficult interactions with my doctors, nurses, and other health care providers. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 10. I am confident that I am can put my loved one’s illness into proper perspective in my life. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 11. I am confident that I have the ability emotionally to help my family work through the issues caused by my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 12. I am confident that I can deal with the physical changes caused by my loved one’s illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 13. I am confident that I can manage what is being asked of me despite this illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 14. I am confident that I have the skills to deal with the pressures the illness is causing in my close relationships. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 15. I am confident that I have ways to manage the side effects caused by treating the cancer. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 16. I am confident that I can keep a positive outlook in spite of the demands of this illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 17. I am confident that I have ways to manage the stress associated with this illness. | | | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

People have different levels of various skills for responding to the challenges and demands of everyday life.  The following items list several things that people are able to do--to a greater or lesser degree--to deal with daily stresses.  For each item, indicate how well you currently can do what it describes.  Please don't indicate what you think you should be able to do, or what you wish you could do.  Be as accurate as you can in reporting your degree of confidence about being able to do each of these things.  Choose from the following responses:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | I cannot do this at all | I can do this just a little bit | I can do this a medium amount | I can do this pretty well | I can do this extremely well |
| I am able to use muscle relaxation techniques to reduce any tension I experience | 0 | 1 | 2 | 3 | 4 |
| I become aware of any tightness in my body as soon as it develops | 0 | 1 | 2 | 3 | 4 |
| I can clearly express my needs to other people who are important to me | 0 | 1 | 2 | 3 | 4 |
| I can easily stop and re-examine my thoughts to gain a new perspective | 0 | 1 | 2 | 3 | 4 |
| It's easy for me to decide how to cope with whatever problems arise | 0 | 1 | 2 | 3 | 4 |
| I can easily recognize situations that make me feel stressed or upset | 0 | 1 | 2 | 3 | 4 |
| When problems arise I know how to cope with them | 0 | 1 | 2 | 3 | 4 |
| I notice right away whenever my body is becoming tense | 0 | 1 | 2 | 3 | 4 |
| It's easy for me to go to people in my life for help or support when I need it | 0 | 1 | 2 | 3 | 4 |
| I am able to use mental imagery to reduce any tension I experience | 0 | 1 | 2 | 3 | 4 |
| I am confident about being able to choose the best coping responses for hard situations | 0 | 1 | 2 | 3 | 4 |
| I can come up with emotionally balanced thoughts even during negative times | 0 | 1 | 2 | 3 | 4 |
| I can ask people in my life for support or assistance whenever I need it | 0 | 1 | 2 | 3 | 4 |