

JEWISH ORTHODOX CAREGIVER SURVEY

A project of

L'Orech Yomim/Center for Healthy Living

Of New York

In collaboration with

The Jewish Community Health Initiative

Case Western Reserve University, Cleveland

1. Consent Form

BEFORE DOING THE SURVEY, PLEASE READ THE FOLLOWING CONSENT FORM.

IF YOU AGREE TO PARTICIPATE, PLEASE CHECK OFF THE BOX AT THE BOTTOM.

Please read the following informed consent form. If you have any questions about doing the survey, please call Rabbi Reuven Becker at 718-300-0234 Dr. Mendel Singer at 216-368-1951 or e-mail jewhealth@case.edu. You are under no obligation to complete this survey and may quit at any time. Thank you.

INFORMED CONSENT DOCUMENT

Caregiver Burden and Community Services in the Orthodox Jewish Community

You are being asked to participate in a research study about caregivers in the Orthodox Jewish community. You responded to an announcement that was directed at people who are connected with an Orthodox Jewish congregation or Orthodox Jewish community e-mail list. Please read this form and ask any questions that you may have before agreeing to participate.

In collaboration with the L'Orech Yomim/Center for Healthy Living, Inc., the Jewish Community Health Initiative at Case Western Reserve University is conducting this study.

Background Information

The purpose of this research is to learn more about the demands upon Orthodox Jewish caregivers and how well the Jewish community is helping them to be successful in their difficult task.

Procedures

If you agree to be a participant in this research, we would ask you to complete a brief (10-15 minutes) survey.

Risks and Benefits to Being in the Study

This research has no foreseeable risks.

The benefits of participation are that the results of this survey can be used to identify needs of Orthodox Jewish caregivers and advocate for additional community services. This may end up directly benefiting participants, as well as others.

Compensation

There is no compensation for completing this survey.

Confidentiality

Survey responses are stored anonymously, without any means of linking responses to participants. The records of this research will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records will be kept in a locked file, and access will be limited to the researchers, the University review board responsible for protecting human participants, and regulatory agencies.

Voluntary Nature of the Study

Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University or the L'Orech Yomim/Center for Healthy Living, Inc. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

Contacts and Questions

The researchers conducting this study are Dr. Mendel Singer and Rabbi Reuven Becker. You may ask any questions you have now. If you have any additional questions, concerns or complaints about the study, you may contact them at 216-368-1951 (Dr. Singer) and 718-300-0234 (Rabbi Becker).

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher (s) about; (1) questions, concerns or complaints regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH 44106-7230.

You will be given a copy of this form for your records.

Statement of Consent

I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age.

I AGREE TO PARTICIPATE

(Place Check or Mark in box)

2. General

1. For what relative are you a caregiver? If more than one, complete this survey for the person for whom you do the most caregiving.

Father

Mother

Grandmother

Grandfather

In-Law (please specify)

2. What is your relative's age as of last birthday?

3. Where does your relative for whom you are caregiving live?

- In his/her own home
- With me intermittently
- With me full time
- In an assisted living community, nursing home or other facility where some care is provided by others
- Other (please specify)

4. How far away does your relative live if he/she does not live with you?

- Less than 20 minutes travel time
- Less than one hour travel time
- One to two hours travel time
- Over two hours travel time
- Not applicable

5. Which of the following caregiver services do you perform? (Check all that apply)

- Prepare meals
- Help with self-care (e.g., bathing, dressing)
- Giving medications, pills or injections
- Taking to doctor visits
- Managing financial affairs (bill paying, banking)
- Arranging/supervising paid care services
- Shopping
- Keeping company/providing emotional support
- Other (please specify)

6. Which of the following best describes your practice of Judaism?

- Orthodox
- Non-Orthodox
- Unaffiliated

7. Which of the following best describes your relative's practice of Judaism?

- Orthodox
- Non-Orthodox
- Unaffiliated

8. What would you say is the main problem or illness your relation has?

- Diabetes
- Cancer
- Normal aging
- Arthritis
- Alzheimer's/confusion
- Mental/emotional illness
- Heart disease
- Other (please specify)

9. Do you feel that because of your parent/grandparent/in-law that you don't have enough time for yourself?

- Nearly Always
- Quite Frequently
- Sometimes
- Rarely
- Never

10. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?

- Nearly Always
- Quite Frequently
- Sometimes
- Rarely
- Never

11. Do you feel strained when you are around your parent/grandparent/in-law?

Nearly Always

Quite Frequently

Sometimes

Rarely

Never

12. Do you feel uncertain about what to do about your relative?

Nearly Always

Quite Frequently

Sometimes

Rarely

Never

13. Do you feel lacking in your observance of honoring your parent/grandparent/in-law?

Nearly Always

Quite Frequently

Sometimes

Rarely

Never

3. Parent/Grandparent/In-Law

14. How well does your relative speak English?

Very Well

Well

Not Well

Not At All

15. How well does your relative understand English?

Very Well

Well

Not Well

Not At All

16. What is your relative's primary language?

English

Russian

Hebrew

Yiddish

Farsi

Spanish

Other (please specify)

17. Language problems have limited my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

18. Transportation problems have limited my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

19. Limited finances have limited my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

20. My relative is uncomfortable using community services because the environment is not Jewish enough.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

21. Sabbath and Holiday observance has limited my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

22. Adherence to other religious practices such as modesty in dress and dietary laws have limited my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

23. Practicing Jewish tradition does not limit my relative's use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

4. Caregiver

24. Do you have siblings?

Yes

No

25. If "Yes," how far away do your siblings live?

Less than 20 minutes travel time

Less than one hour travel time

One to two hours travel time

Over two hours travel time

26. Do your siblings provide physical, emotional, and/or financial assistance?

Yes

No

27. If "Yes," how often?

Daily

Weekly

Monthly

Upon request

28. How frequently do other non-paid caregivers participate in your relative's care?

- Daily
- Weekly
- Monthly
- Upon request

29. My caregiver burden is made lighter by the emotional support of my family.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

30. My caregiver burden is made lighter by the physical support of my family.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

31. Are you aware of any community support groups for caregivers?

- Yes
- No

32. I would be interested in participating in a support group for caregivers if I were comfortable with the group.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

33. Are you aware of any counseling services for caregivers?

Yes

No

34. I would be interested in counseling services for caregivers if I was comfortable with the counselor and setting.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

35. How well do you speak English?

Very Well

Well

Not Well

Not At All

36. How well do you understand English?

Very Well

Well

Not Well

Not At All

37. What is your primary language?

English

Russian

Hebrew

Yiddish

Farsi

Spanish

Other (please specify)

38. Language problems have limited my use of community services that might reduce caregiver burden.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

39. Transportation problems have limited my use of community services that could reduce my caregiver burden.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

40. Limited finances have limited my use of community services that might reduce caregiver burden.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

41. What two aspects of caregiving are the most difficult or challenging for you?

Lack of time for self

Obtaining Medical and Personal care for my loved one

Physical assistance (getting in/out of beds and chairs, lifting)

Financial situation, costs

Toileting/Dealing with incontinence

Other (please specify)

42. In looking for information or services to help with the challenges of caregiving I have turned to the following sources (Check all that apply):

- Health professional (Doctor, nurse, health worker, pharmacist, etc.)
- Friends or family
- Government programs or agencies
- Disease-specific organization
- Synagogue
- Rabbi
- Internet
- Other source for information [Books, brochures, library, radio or TV, community organizations]
- None sought
- None needed

43. How much success did you have at finding help?

- A great deal
- A moderate amount
- A little
- None at all

44. How often do you read a secular newspaper/magazine (e.g., New York Times, USA Today)?

- Daily
- Weekly (e.g. Sundays)
- Not on a regular basis
- Never

45. Do you only read Jewish newspapers/magazines?

- Yes
- Most of the time
- No

46. How often do you listen to the radio?

- Every Day
- Often
- Sometimes
- Rarely or Never

47. Do you watch television in your home?

- Yes
- No

48. Do you use the Internet at home?

- Every Day
- Often
- Sometimes
- Rarely
- Never at home or work
- Never at home, but at work

49. I am uncomfortable using community services that might help reduce caregiver burden because the environment is not Jewish enough.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

50. Sabbath and Holiday observance has limited my use of community services that might reduce caregiver burden.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

51. Other than Sabbath and Holiday observance, practicing Jewish tradition does not limit my use of community services.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

52. Seeking community services to reduce my caregiver burden would make me feel guilty.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

53. I feel conflict in asking for assistance as it may suggest that I am lacking in my observance of honoring my parent/grandparent/in-law.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

54. When caring for my relative, I feel like I am failing in my observance of honoring my parent/grandparent/in-law.

Strongly Agree

Agree

Neither Agree nor Disagree

Disagree

Strongly Disagree

55. The opinion of my religious leaders is important to me.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

56. The opinion of others in my Jewish community is important to me.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

5. Community Services

57. My local Jewish Community provides the needed services for my relative.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

58. My local Jewish Community provides the services that I need as a caregiver.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

6. About YOU

59. What is your gender?

Female

Male

60. Your Age

61. Years of Secular Education

62. How many years have you been a caregiver?

63. Where do you live? (city, state)

64. Comments/Suggestions/Feedback Regarding This Pilot Survey:

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Y o u !!