

August 7, 2009

NOTE TO THE REVIEWER OF: OMB No. 1220-0141
Cognitive and Psychological Research

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SUBJECT: Submission of Materials for ATUS Eldercare Focus Groups

Please accept the enclosed materials for approval under the OMB clearance package #1220-0141, "Cognitive and Psychological Research." In accordance with our agreement with OMB, we are submitting a brief description of the research, and the materials to be used in the research at least two weeks prior to the beginning of the study.

We will be conducting the focus groups with respondents recruited from the DOL Eldercare Support Group, Alzheimer's Family Day Center, and other caregiver organizations in the Metro DC area, as well as the general public. Special effort will be made to recruit participants who are engaged in providing unpaid caregiving to elderly family members or friends. The maximum number of burden hours is estimated to be 32.

If there are any questions regarding this project, please contact Christine Rho at (202) 691-7399.

Attachments

Focus Groups on ATUS Eldercare

I. PURPOSE

The purpose of this project is to study methods of measuring informal eldercare: the amount of time spent in providing unpaid assistance to older adults in need of care. The objective is to identify the key issues in eldercare, through focus groups with caregivers. This will involve conceptual issues of defining what comprises informal eldercare and related factors.

II. BACKGROUND

Informal eldercare is a major source of assistance for the elderly in the community. Families, not nursing facilities or paid professionals, provide the majority of elder care in this country (Abel, 1991; Pyke & Bengtson, 1996). Informal eldercare is unpaid assistance, generally provided by a family member to an elderly parent or spouse.

There is increasing use of the term “informal eldercare” to connote the type of support and assistance given to older adults by family caregivers. Although there may be similarities in the day-to-day activities of caring for a child or an elderly parent, there are also distinct differences between the two situations that make it a challenge for researchers to study eldercare. It is difficult to define eldercare specifically since there are broad generalities in the type of caregiving, ranging from very specific care services, e.g., bathing or dressing, to providing a vast range of general assistance, such as companionship. There is also a lack of consistent terms used to refer to eldercare and the recipients of care, which is another source of challenge in developing a good measure of eldercare.

Recent census data (U.S. Bureau of the Census, 2000) show a demographic change in the U.S. population, which reflect not only a large numerical and proportionate increase in the older population, but also the aging of the elderly population itself. Interest in eldercare has increased because of the growing population of older adults and because of the trend in caregiving, which has shifted from formal or institutional care to an informal or community-based care. Such trends are due to several factors: 1) current cost containment measures that transfer caregiving work from public social services to unpaid family members (Pyke & Bengtson, 1996), and 2) longer life spans, which increases the number of people needing care. Today, more American families than ever before are involved in providing some type of care or support to an elderly family member (Abel, 1991; Anastas, 1990). Knowledge about aging and informal caregiving is becoming increasingly important and so is the need for quality data on how much resources are devoted to eldercare, and how this impacts other aspects of a person’s life. The American Time Use Survey (ATUS) proposes to measure how many unpaid hours Americans are spending in caring for an elderly person. The purpose of this research project is to develop survey questions for measuring informal eldercare with the ATUS collection instrument. Extensive literature search on the topic of Eldercare has been completed, as well as interviews with a panel of experts on Eldercare research. From these research efforts, ATUS has drafted a conceptual definition of Eldercare and is seeking feedback from the target population of eldercare providers.

III. RESEARCH METHOD

I. Methodology

The OSMR will conduct 2-3 focus groups:

A. Focus Group with Caregivers (1-2 groups of 7 participants)

- The primary purpose of the focus group will be to obtain reactions on the concept of informal eldercare from those who are directly responsible for providing care. This focus group on the caregiver's perspective will help to supplement the information gathered from known experts and the current literature.
- The focus group will also explore ways to measure a very common, but under-reported type of caregiving, which is emotional support and companionship. Emotional support is often overlooked as a caregiving activity, although experts estimate that this is the most common form of eldercare. We will explore whether respondents consider this type of support as "caregiving" and whether they would be able to report how much time they spent in this type of care.
- The focus group will be comprised of approximately 10 adults (male and female) who spend at least 3 hours per week in caring for an older adult.

B. Focus Group with Older Adults (1 group of 7 participants)

- The purpose of this focus group is to gain insight on eldercare from the perspective of older adults. Older adults can offer their perspectives on what they think constitutes care. Older adults may be most knowledgeable about their own needs and how they are met.
- Additionally, older adults are also informal caregivers. Many older adults provide hours of informal care to elderly spouses who need assistance. Therefore, any measure we develop must also be able to address older adult caregivers.
- We will compare the findings from this focus group with those of caregiver focus group to assess whether there are shared perspectives on what eldercare services are.
- A group of ten older adults (aged 65-85) will be recruited from the community for the focus group. We may conduct the focus group at a remote site, such as an elderly community center or adult day care center, in order to ease the burden of travel for this group of participants.

III. Participants and Burden Hours

Approximately 21 participants will be recruited from the general population, with special care to recruit those who spend more than three hours per week on providing eldercare. The estimated time to complete the session is 1.5 hours. Approximately 31.5 hours will be used. Participants will be reimbursed \$60.00 for their participation in the focus group.

IV. Confidentiality

Participants will read and sign a Consent Form. They also will be verbally informed about what they will be asked to do, that their participation is voluntary, that the session will be audio taped, and that the information is protected under the Privacy Act in accordance with the Privacy Act statement on the back of the Consent Form) and asked to give verbal consent. (See Attachment A: Consent Form).

V. Attachments

- A. Consent Form
- B. Focus Group Protocol

Attachment A

Consent Form

The Bureau of Labor Statistics (BLS) is conducting research to increase the quality of BLS surveys. This study is intended to suggest ways to improve the procedures the BLS uses to collect survey data.

The BLS, its employees, agents, and partner statistical agencies, will use the information you provide for statistical purposes only and will hold the information in confidence to the full extent permitted by law. In accordance with the Confidential Information Protection and Statistical Efficiency Act of 2002 (Title 5 of Public Law 107-347) and other applicable Federal laws, your responses will not be disclosed in identifiable form without your informed consent. The Privacy Act notice on the back of this form describes the conditions under which information related to this study will be used by BLS employees and agents.

During this research you may be audio and/or videotaped, or you may be observed. If you do not wish to be taped, you still may participate in this research.

We estimate it will take you an average of 90 minutes to participate in this research (ranging from 85 minutes to 95 minutes).

Your participation in this research project is voluntary, and you have the right to stop at any time. If you agree to participate, please sign below.

Persons are not required to respond to the collection of information unless it displays a currently valid OMB control number. OMB control number is 1220-0141 and expires February 29th, 2012.

I have read and understand the statements above. I consent to participate in this study.

Participant's signature

Date

Participant's printed name

Researcher's signature

OMB Control Number: 1220-0141
Expiration Date: [02/29/12]

PRIVACY ACT STATEMENT

In accordance with the Privacy Act of 1974, as amended (5 U.S.C. 552a), you are hereby notified that this study is sponsored by the U.S. Department of Labor, Bureau of Labor Statistics (BLS), under authority of 29 U.S.C. 2. Your voluntary participation is important to the success of this study and will enable the BLS to better understand the behavioral and psychological processes of individuals, as they reflect on the accuracy of BLS information collections. The BLS, its employees, agents, and partner statistical agencies, will use the information you provide for statistical purposes only and will hold the information in confidence to the full extent permitted by law. In accordance with the Confidential Information Protection and Statistical Efficiency Act of 2002 (Title 5 of Public Law 107-347) and other applicable Federal laws, your responses will not be disclosed in identifiable form without your informed consent.

Attachment B: Focus Group Protocol

FOCUS GROUP PROTOCOL: Eldercare Providers

STUDY PURPOSE: To explore opinions of eldercare providers, who may be providing eldercare for a family member or non-relative, in order to develop survey questions about eldercare for the ATUS.

AGENDA FOR PLANNED DISCUSSIONS:

Category of Information to be Covered	Approx. Time Duration
Introduction/Ground Rules/Welcome/Consent Form	15 minutes
Issue A: Baseline Q's about Eldercare Experience	20 minutes
Issue B: Specific Q's about Eldercare Definition	25 minutes
Issue C: Specific Q's about Elderly or Spousal Eldercare	10 minutes
Closure	15 minutes
Total Time Allotted	85 minutes (plus 5 min for logistics)

INTRODUCTIONS

Thank you for taking the time to come talk with us today. My name is _____ and I'm a researcher at the Bureau of Labor Statistics. The Bureau of Labor Statistics is trying to measure how much time people spend providing eldercare to family members or friends. This will be a part of the American Time Use Survey. We've asked you to participate in this discussion so that we can hear first-hand from the people who are taking care of an elderly adult. We would like your feedback on how we are defining eldercare.

[Introduce any observers and note-takers]

To allow conversation to flow more smoothly, I have the following ground rules so we will all be moving in the same direction and to ensure that the session will end on time.

- Please talk one at a time.
- Please allow someone to finish their point before talking.
- Please talk as loudly as possible so all can hear.
- Avoid side conversations with your neighbor.
- I need to hear from everyone; however, you don't have to answer every question.
- Work for equal air time so no one talks too much or too little.
- Allow for different points of view; there are no right or wrong answers.
- Say what you believe, whether or not anyone agrees with you.
- Everything discussed today will be confidential and individual comments will not be identified. We will be speaking off the record today.
- With your permission, I will be tape recording this conversation for my own note-taking purposes.

Are there any questions about what I have just covered? If there are no other questions, then let's begin.

Please introduce yourself and tell us your first name, for whom you provide eldercare, and your favorite activity or hobby (when you have free time).

ISSUE A: BASELINE QUESTIONS ABOUT PERSONAL EXPERIENCES WITH ELDERCARE

Before we begin our discussion, I want to ask some general questions about your experience with eldercare.

1. Thinking about all the caregiving you do, about how many hours per week do you spend providing eldercare?
2. **Picture Deck Exercise.** You will be looking at a collection of pictures that represent a wide variety of images, feelings, and attitudes. I'd like you to choose one picture that best characterizes your feelings or experiences with eldercare. *[The purpose of this task is to get the participants to start verbalizing, in their own words, how they think/feel about eldercare. This is a warm-up exercise.]*
 - Tell about the connection or associations that you made to the picture.
 - Did anyone choose the same pictures? Tell me about your reason for picking this picture.

ISSUE B: SPECIFIC QUESTIONS ABOUT ELDERCARE DEFINITION

Let's turn our attention to talking more specifically about what is eldercare.

3. In your opinion, what activities do you consider to be eldercare?
Probe: Tell me about the things you do when caring for your spouse/partner.
[List on Flip Chart]
4. Now let's think about the flip side. What are NOT eldercare activities? In your opinion, what types of activities should we exclude from eldercare?
Probe: *[If needed]* For example, lawn care. What if you were to help mow the lawn, because your spouse is no longer able to? Would you consider that to be eldercare?
[List on Flip Chart]
5. **Definition Exercise.** Now I am going to give you our working definition of eldercare. Please take a moment to read it. As you read it, I'd like you to circle any words or phrases that you agree with or think is important to eldercare. And I'd like you to cross-out any words or phrases you disagree with or find offensive or you think is not very important to eldercare. *[Hand-out Eldercare Definition Exercise sheet and pencil.]*

Eldercare Definition

Eldercare is providing care or assistance to an individual over the age of 65 because of a need induced by aging or a medical condition. This care can be provided either by a family member or non-relative, but it cannot be provided as part of one's paid job. There is an

expectation that the care will be provided on a long-term basis. The care is not provided for a temporary condition from which an individual will recover, such as a broken leg, unless the temporary condition is part of ongoing need for care. Care can be provided to in either a care facility, such as a nursing home, or in a non-institutionalized setting, such as the person's home.

6. Let's discuss this definition. What are some words/phrases that you circled?

Probe: Did anyone circle:

- Over the Age 65
- Medical condition
- Family member
- Non-relative
- Cannot be paid
- Long-term basis
- Ongoing need; Temporary condition
- Institutionalized; Nursing home; Care facility
- Non-institutionalized; In person's home

Probe: What, if anything, did you cross out? Tell me about some of the reasons you had for crossing them out.

7. Have we missed anything in our definition that you feel is important to eldercare?

ISSUE C: SPECIFIC QUESTIONS ABOUT ELDERLY OR SPOUSAL ELDERCARE

I'd like to specifically talk about your role as a spouse and an eldercare provider.

8. One of the challenges we've encountered when thinking about how we will measure the amount of time people spend in providing eldercare is the question of how to distinguish the activities that you've always done to help your spouse in the past versus the help you're providing because he or she can no longer do it for themselves. For example, if you are cooking and providing meals for your spouse – is that part of eldercare? Or have you always done the majority of cooking throughout the years?
- a. How do you think about these activities now?
 - b. How would your spouse think about these activities? Would s/he consider it as receiving care or would s/he consider it to be just a part of marriage or partnership?

WRAP-UP

This session is almost over and before we end, I'd like to get your final thoughts.

9. Is there any topic that we've missed that you think is important to our discussion about measuring eldercare?

Thank you very much for participating today; your thoughts and feedback is very helpful. We realize that you probably do not have a lot of free time, and we really appreciate that you were able to spend this hour with us. If you have any other thoughts, comments or questions following this session, please feel free to contact me at [*give email address or business card*]. Or if you're interested in finding out more about the American Time Use Survey, here is the website address: www.bls.gov/tus