

Appendix: Interview Guide

Gaining Access to Personal Health Information of the Person with Dementia

1. What information about the person with dementia's health do you (or caregivers) need to access?
2. How do you (or caregivers) use this information?
3. Where do you (or caregivers) get the information?
 - a. How do you (or caregivers) get the information?
 - b. In what form?
4. What problems do you (or caregivers) experience in getting or using the information?
5. How do you (or caregivers) deal with these problems?

Tracking Patient's Health

6. What information about the patient's health do you (or caregivers) need to track?
 - a. How do you (or caregivers) track the information?
7. How do you (or caregivers) use this information?
8. Where do you (or caregivers) get the information?
9. What problems do you (or caregivers) experience in tracking or using the information?
10. How do you (or caregivers) deal with these problems?

Managing Medications & Behavioral and Psychological Symptoms of Dementia

11. For caregivers only: Is the patient on medications to manage behavior symptoms?
 - a. If Yes: How do you manage the patient's medications?
12. What information do you (or caregivers) need to manage medications? What information do you (or caregivers) need to manage behavior symptoms?
13. How do you (or caregivers) use this information?
14. Where do you (or caregivers) get this information?
 - a. How do you (or caregivers) get the information?

- b. In what form?
- 15. What problems do you (or caregivers) experience in getting or using the information?
- 16. How do you (or caregivers) deal with these problems?

Coordinating with Healthcare and Social Service Providers

- 17. How do you (or caregivers) connect with others to get help (e.g., health care provider, social service provider, legal service provider, family member or friends)?
 - a. What information do you (or caregivers) need to help connect with them?
- 18. How do you (or caregivers) use the information?
- 19. Where do you (or caregivers) get information to help connect with others?
 - a. How do you (or caregivers) get the information?
 - b. In what form is the information?
- 20. What problems do you (or caregivers) experience in getting or using information to connect with others?
- 21. How do you (or caregivers) deal with these problems?

Learning about Dementia, its Progression, and How to Provide Care

- 22. How do you (or caregivers) learn about the day-to-day activities involved in caregiving?
 - a. What information do you (or caregivers) need the most?
- 23. Where do you (or caregivers) get the information?
 - a. How do you (or caregivers) get the information?
 - b. In what form is the information?
 - c. If they don't mention online resources, ask: Do you (or caregivers) access online resources, such as YouTube videos? What online resources? How do you (or caregivers) find them? What do you (or caregivers) think about them?
- 24. How do you (or caregivers) use this information?
- 25. What problems do you (or caregivers) experience in getting or using this information?
 - a. What problems do you (or caregivers) experience in *understanding* this information?
- 26. How do you (or caregivers) deal with these problems?

Appendix: Survey

1. The most recent time you looked for health information about health or medical topics, where did you go first? Select only one.
 - ☐ Books
 - ☐ Brochures, pamphlets, etc.
 - ☐ Community organization
 - ☐ Family
 - ☐ Friend/Co-worker
 - ☐ Doctor or health care provider
 - ☐ Internet
 - ☐ Library
 - ☐ Magazines
 - ☐ Newspapers
 - ☐ Telephone information number
 - ☐ Complementary, alternative, or unconventional practitioner

2. The most recent time you looked for information about health or medical topics, who was it for?
 - ☐ Myself
 - ☐ Someone else
 - ☐ Both myself and someone else

3. Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
<input type="radio"/> It took a lot of effort to get the information you needed				
<input type="radio"/> You felt frustrated during your search for the information				
<input type="radio"/> You were concerned about the quality of the information				
<input type="radio"/> The information you found was hard to understand				

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research

Topic	Item No.	Guide Questions/ Description	Author Responses
Domain 1: Research team and reflexivity			
<u>Personal Characteristics</u>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	[removed for peer review] and [removed for peer review] conducted interviews with providers. Two staff members (who are not co-authors) conducted interviews with caregivers.
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	[removed for peer review]
Occupation	3	What was their occupation at the time of the study?	[removed for peer review]
Gender	4	Was the researcher male or female?	[removed for peer review]
Experience and training	5	What experience or training did the researcher have?	[removed for peer review] have formal training in qualitative research methods. The two staff members had 2+ years of experience conducting interviews with Spanish- and English-speaking Latino study participants. [removed for peer review] trained the two staff members on interviewing techniques and the protocol for the present study.
<u>Relationship with participants</u>			
Relationship established	6	Was a relationship established prior to study commencement?	No interviewer had an established relationship with study participants prior to study commencement.
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	The study participants did not have any personal knowledge of the interviewers.
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	[removed for peer review]
Domain 2: Study design			
<u>Theoretical framework</u>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content	Reported in "Data Analysis" section.

		analysis	
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Reported in "Participant Recruitment" section.
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	Reported in "Participant Recruitment" section.
Sample size	12	How many participants were in the study?	Reported in "Participant Recruitment" section.
Non-participation	13	How many people refused to participate or dropped out? Reasons?	Reported in "Participant Recruitment" section.
<u>Setting</u>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	Reported in "Participant Recruitment" section.
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No one besides the study participant and the interviewer was present.
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Reported in "Characteristics of Latino Caregivers" section.
<u>Data collection</u>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Reported in "Data Collection" section. The interview guide was pilot tested.
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No repeated interviews were carried out.
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Reported in "Data Collection" section.
Field notes	20	Were field notes made during and/or after the interview or focus group?	Yes, field notes were made during the interviews.
Duration	21	What was the duration of the interviews or focus group?	Reported in "Data Collection" section.
Data saturation	22	Was data saturation discussed?	No, data saturation was not discussed.
Transcripts returned	23	Were transcripts returned to participants for comment and/or corrections?	No, transcripts were not returned to participants for comment and/or corrections.
Domain 3: analysis and findings			
<u>Data analysis</u>			
Number of data coders	24	How many data coders coded the data?	Three members of the research team coded the data.

Description of the coding tree	25	Did authors provide a description of the coding tree?	Reported in “Data Analysis” section. The codebook is available upon request.
Derivation of themes	26	Were themes identified in advance or derived from the data?	The themes were derived in advance.
Software	27	What software, if applicable, was used to manage the data?	Reported in “Data Analysis” section.
Participant checking	28	Did participants provide feedback on the findings?	No, the participants did not provide feedback on the findings.
<u>Reporting</u>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, quotations were presented to illustrate findings. A description of the caregiver was provided as context for each quote.
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Reported in “Results” section.
Clarity of major themes	31	Were major themes clearly presented in the findings?	Reported in “Results” section.
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Reported in “Results” section.

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Additional Guidelines for Completing the COREQ Checklist for *Journal of Applied Gerontology*:

- This checklist will be published online as supplementary material and we require it to be in the form of a publishable table. Please make sure that material does not bleed outside of cells, etc.
- This checklist is designed to direct readers to relevant material in the manuscript. Where applicable, please direct readers to various sections of the manuscript, such as a Methods section, Conceptual Framework, table or figure. Pages may shift during the publication process so please avoid directing readers to specific page numbers.
- This checklist also is designed to supplement information that may not be reported in the text and/or provide additional details related to information that is reported in the text.

Once you have completed this checklist, please save a copy and upload it as part of your *Journal of Applied Gerontology* submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate supplemental file.