



GERIATRIC EDUCATION AND RESEARCH IN AGING SCIENCES CENTRE (GERAS)

Hamilton Health Sciences St Peter's Hospital Site
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Project Title: “Understanding the educational and support needs of caregivers of patients diagnosed with dementia”

CAREGIVER INTERVIEW GUIDE

A. Preamble

Hello. Thank you for agreeing to be interviewed for our research. I want to learn from you about the educational and support needs you have required and used since your family member has received the diagnosis of dementia here at the geriatric assessment clinic in St. Peter's Hospital. You do not need to answer any questions you don't want to. You can stop the interview at any time. If you decide you don't want to answer certain questions, or you decide to stop the interview, there will be no consequences for the care and support that you and your loved one receive. Similarly, the answers you give won't in any way affect that care or support. I will be recording the interview and making notes. Do I have your consent to continue? Do you have any questions before we begin?

B. Complete Demographic Data Collection Form

C. Questions for Caregivers after the first visit where they received the patient received the diagnosis of dementia

- 1) Please tell me what are the sorts of educational materials and information **you received from the doctors or nurses or case manager** at the initial visit in the geriatric clinic when your family member received the diagnosis of dementia?
- 2) Since your visit, have you called the clinic for guidance or help?

Probing Questions:

If yes, who did you speak to? What are the sorts of things did you need help with? (e.g., medical issues, activity of daily living or personal care issues, finances, stress, etc.) What sorts of assistance (e.g., education about dementia, more information about available resources/assistance and how to access them, etc.) did you seek or inquire about?

- 3) Since your clinic visit, did you try other ways of learning about dementia and the sources of support available to you in the community as a caregiver of someone with dementia?

Probing Questions:

If yes, which ones (e.g., websites, books, friends, place of worship, etc.)? What did you find more and less helpful about these resources? What did you feel you learned from them?

- 4) Have you made contact with any health care, government or voluntary sector organizations (e.g., Alzheimer Society First Links program, CCAC, Veteran's Affairs)?

Probing Questions:

If yes, did you make use of any of their services?

Can you tell me more about that? How often do you go / do they visit? What sorts of things do they help you with etc.?

- 5) Have you made contact with any other support networks such as your religious community (church, mosque, etc.), family, friends?

Probing Questions:

If yes, can you describe what supports you have received from them?

Can you tell me more about that? How often do you go / do they visit? What sorts of things do they help you with etc.?

- 6) Are there any other places you might be receiving help that we've not asked about?

- 7) What do you think are the most important resources or information that health professionals could offer to persons like yourself who are caring for family members with dementia?

Probing Questions:

What information do you think it is important for caregivers like yourself to have or know when they are told their loved one has dementia?

What contacts, services, or resources do you think it is important for dementia caregivers know about?

- 8) If you had the opportunity to offer advice to a caregiver of a person who was just diagnosed with dementia – what would your advice be?

- 9) We're coming to the end of our interview, so was there anything else you'd like to tell me about resources, information or other material that could be offered to help caregivers of patients diagnosed with dementia that you haven't already told me?

C. Questions for Caregivers of patients returning for second or subsequent visits to the Clinic

Please tell me what are the sorts of educational materials and information **you received from the doctors or nurses or case manager** at the initial visit in the geriatric clinic when your family member received the diagnosis of dementia?

- 1) Between the initial visit where the diagnosis of dementia was made and the following visit to the clinic, did you call the clinic for guidance or help?

Probing Questions:

If yes, who did you speak to? What are the sorts of things you needed help with? (e.g., medical issues, activity of daily living or personal care issues, finances, stress, etc.) What sorts of assistance (e.g., education about dementia, more information about available resources/assistance and how to access them, etc.)?

- 2) Between the initial visit where the diagnosis of dementia was made and the following visit to the clinic, did you try other ways of learning about dementia and the sources of support available to you in the community as a dementia caregiver?

Probing Questions:

If yes, which ones (e.g., websites, books, friends, place of worship, etc.)? What did you find more and less helpful about these resources? What did you feel you learned from them?

- 3) Have you made contact with any health care, government or voluntary sector organizations (e.g., Alzheimer Society First Links program)?

Probing Question:

If yes, did you make use of any of their services?

- 4) What are the sorts of issues did you need assistance with when you returned to the clinic after the initial visit?

Probing Questions:

Did you feel you needed help with any of the following matters: medical issues, activity of daily living and personal care issues, finances, stress?

- 5) What do you think are the most important resources or information that health professionals could offer to persons like yourself who are caring for family members with dementia?

Probing Questions:

What information do you think it is important for caregivers like yourself to have or know when they are told their loved one has dementia?

What contacts, services, or resources do you think it is important for dementia caregivers know about?

- 6) If you had the opportunity to offer advice to a caregiver of a person who was just diagnosed with dementia – what would your advice be?
- 7) We're coming to the end of our interview, so was there anything else you'd like to tell me about resources, information or other material that could be offered to help caregivers of patients diagnosed with dementia that you haven't already told me?

D. Conclusion

Thank you so much for taking the time to help me better understand the needs of caregivers like yourself.