12. Caregivers

Related Core CFI Question: 6, 12, 14

GUIDE TO INTERVIEWER: This module is designed to be administered to individuals who provide caregiving for the individual being assessed with the CFI. This module aims to explore the nature and cultural context of caregiving, and the social support and stresses in the immediate environment of the individual receiving care, from the perspective of the caregiver.

INTRODUCTION FOR THE CAREGIVER: People like yourself who take care of the needs of patients are very important participants in the treatment process. I would like to understand your relationship with [INDIVIDUAL RECEIVING CARE] and how you help him/her with his/her problems and concerns. By *help*, I mean support in the home, community, or clinic. Knowing more about that will help us plan his/her care more effectively.

Nature of relationship

- 1. How long have you been taking care of [INDIVIDUAL RECEIVING CARE]? How did this role for you start?
- 2. How are you connected to [INDIVIDUAL RECEIVING CARE]?

Caregiving activities and cultural perceptions of caregiving

- 3. How do you help him/her with the [PROBLEM] or with day-to-day activities?
- 4. What is most rewarding about helping him/her?
- 5. What is most challenging about helping him/her?
- 6. How, if at all, has his/her [PROBLEM] changed your relationship?

Sometimes caregivers like yourself are influenced in doing what they do by cultural traditions of helping others, such as beliefs and practices in your family or community. By cultural traditions I mean, for example, what is done in the communities you belong to, where you or your family are from, or among people who speak your language or who share your race or ethnic background, your gender or sexual orientation, or your faith or religion.

- 7. Are there any cultural traditions that influence how you approach helping [INDIVIDUAL RECEIVING CARE]?
- 8. Is the amount or kind of help you are giving him/her different in any way from what would be expected in the community that you come from or the one he/she comes from? Is it different from what society in general would expect?

Social context of caregiving

- 9. [IF CAREGIVER IS A FAMILY MEMBER:] How do you, as a family, cope with this [PROBLEM]?
- 10. Are there others, such as family members, friends, or neighbors, who also help him/her with the [PROBLEM]? If so, what do they do?
- 11. How do you feel about how much or how little others are helping with his/her [PROBLEM]?

Clinical support for caregiving

- 12. How do you see yourself helping to provide care to [INDIVIDUAL RECEIVING CARE] now and in the future?
- 13. [IF UNCLEAR:] How do you see yourself helping with the care that he/she receives in this clinic?
- 14. How can we make it easier for you to be able to help [INDIVIDUAL RECEIVING CARE] with the [PROBLEM]?