National Study of Caregiving

Section	AC	[ASPECTS OF CAREGIVING]	Sequence: 6

BOX AC1PRE

BOX AC1PRE	NOT ON FILE

QUESTION TEXT:

If SP DECEASED flag = 1 (YES), go to AC5.
Otherwise, go to AC1PRE.

AC1PRE

AC1PRE	NOT ON FILE

QUESTION TEXT:

Now we have a few questions about your relationship with {SP}.

PRESS 1 AND ENTER TO CONTINUE

AC1

cac7joylevel	C7 AC1 ENJOY BEING WITH SP

QUESTION TEXT:

How much do you enjoy being with {SP}? Would you say a lot, some, a little, or not at all?

CODES

1	A LOT
2	SOME
3	A LITTLE
4	NOT AT ALL
	REFUSED
	DON'T KNOW

AC2

cac7arguelv	C7 AC2 LEVEL SP ARGUES WITH YOU

QUESTION TEXT:

How much does {SP} argue with you? Would you say a lot, some, a little, or not at all?

CODES

1	A LOT
2	SOME
3	A LITTLE
4	NOT AT ALL
	REFUSED
	DON'T KNOW

AC3

cac7spapprlv	C7 AC3 LEVEL SP APPRECIATES YOU

QUESTION TEXT:

How much does {SP} appreciate what you do for {him/her}?

[Would you say a lot, some, a little, or not at all?]

CODES

1	A LOT
2	SOME
3	A LITTLE

4   NOT AT ALL
           REFUSED
           DON'T KNOW

AC4   **cac7nerveslv**   C7 AC4 LEVEL SP ON YOUR NERVES

QUESTION TEXT:

How often does {he/she} get on your nerves?

[Would you say a lot, some, a little, or not at all?]

CODES

1	A LOT
2	SOME
3	A LITTLE
4	NOT AT ALL
	REFUSED
	DON'T KNOW

AC5   **cac7moreconf**   C7 AC5A HLP SP U MORE CNF ABLTY

                   cac7dealbetr   C7 AC5B HLP SP U DEAL W DIFF SIT

                   cac7closr2sp   C7 AC5C HLP SP U R CLOSER TO SP

                   cac7moresat   C7 AC5D HLP SP U STSFY SP CARED4

DISPLAY INSTRUCTIONS:

Use "Same Question Stem" display.

If at AC5a, do not display question text in brackets.
Otherwise, display question text in brackets.

If SP DECEASED flag <> 1 (YES), display "has" in AC5c.
Otherwise, use null display.

If SP DECEASED flag = 1 (YES), display "was" in AC5d.
Otherwise, display "is".

QUESTION TEXT:

{[} Next we have a few questions about your experience helping {SP}. For each statement I read, please tell me whether this describes your situation very much, somewhat, or not so much.{]}

{variable text [a-d]}

RESPONSE [1] a. Helping {SP} has made you more confident about your abilities.
RESPONSE [2] b. Helping {him/her} has taught you to deal with difficult situations.
RESPONSE [3] c. Helping {SP} has brought you closer to {him/her}.
RESPONSE [4] d. Helping {SP} has given you satisfaction that {he/she} {is/was} well cared for.

CODES

1	VERY MUCH
2	SOMEWHAT
3	NOT SO MUCH
	REFUSED

DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display 'variable text' in the a-d sequence until all rows have been displayed.

AC6	cac7diffinc	C7 AC6A FINANCIAL DIFF HELPING
	cac7diffemo	C7 AC6B EMOTIONAL DIFF HELPING
	cac7diffphy	C7 AC6C PHYSICAL DIFF HELPING

DISPLAY INSTRUCTIONS:
Use "Same Question Stem" display.
If at AC6a, do not display question text in brackets.
Otherwise, display question text in brackets.

If preloaded relationship of SP to Caregiver is 2 (spouse/partner), display "Helping a spouse or partner who has health problems can be difficult."

If preloaded caregiver is related to SP (relationship codes 3-29), display "Helping older relatives can be difficult."

Otherwise, use null display.

If SP DECEASED flag <> 1 (YES), display "Is helping {SP}".
Otherwise, display "Has helping {SP} been".

QUESTION TEXT:
{[} {Helping a spouse or partner who has health problems can be difficult./Helping older relatives can be difficult.} {Is helping {SP}/Has helping {SP} been}… {]}

{variable text [a-c]}

RESPONSE [1] a. financially difficult for you?
REPSONSE [2] b. emotionally difficult for you?
RESPONSE [3] c. physically difficult for you?

CODES

1	YES
2	NO
	REFUSED
	DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.

Display 'variable text' in the a-c sequence until all the rows have been displayed.

BOX AC7	BOX AC7	NOT ON FILE

If AC6a, 6b, and 6c = 2 (NO), RF, or DK, go to BOX AC8.

Otherwise, go to AC7.

AC7	cac7diffinlv	C7 AC7A LEVEL FINANCIALLY DIFF
	cac7diffemlv	C7 AC7B LEVEL EMOTIONALLY DIFF

DISPLAY INSTRUCTIONS:

If AC6a = 1 (YES, FINANCIALLY DIFFICULT), display AC7a.
If AC6b = 1 (YES, EMOTIONALLY DIFFICULT), display AC7b.
If AC6c = 1 (YES, PHYSICALLY DIFFICULT), display AC7c.

Use "Same Question Stem" display.

If at first item, do not display question text in brackets.
Otherwise, display question text in brackets.

If SP DECEASED flag <> 1 (YES), display "is helping {SP}".
Otherwise, display "has helping {SP} been".

QUESTION TEXT:

{[} Please tell me how difficult helping is by picking a number from 1 to 5. The number 5 means very difficult and the number 1 means a little difficult.{]}

{variable text [a-c]}

{RESPONSE [1] a. How financially difficult {is helping {SP}/has helping {SP} been}?}
{REPSONSE [2] b. How emotionally difficult {is helping {SP}/has helping {SP} been}?}
{RESPONSE [3] c. How physically difficult {is helping {SP}/has helping {SP} been}?}

CODES

1	1 A LITTLE DIFFICULT
2	2
3	3
4	4
5	5 VERY DIFFICULT
	REFUSED
	DON'T KNOW

PROGRAMMER INSTRUCTIONS:

Array the responses and variable text columns in the panel.

Display 'variable text' in the a-c sequence until all rows have been displayed.

BOX AC7A   **BOX AC7A**   NOT ON FILE

If ((CA1 = 1 (HELPED WITH CHORES EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA2= 1 (HELPED WITH SHOPPING EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or CA3= 1 (HELPED ORDER MEDS)
or CA4=1 (HELPED WITH BILLS OR BANKING)
or (CA6 = 1 (HELPED WITH PERSONAL CARE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA7= 1 (HELPED GET AROUND HOME EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA9= 1 (HELPED DRIVE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or (CA10= 1 (HELPED USE OTHER TRANSPORTATION EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY))
or CA11A=1 (HELPED TRACK MEDS)
or CA11B=1 (HELPED WITH SHOTS OR INJECTIONS)
or CA11C=1 (HELPED MANAGE MEDICAL TASKS)
or CA11D=1 (HELPED WITH SKIN CARE)
or CA11A2A=1 (HELPED WITH EXERCISE)
or CA11A2B=1 (HELPED WITH SPECIAL DIET)
or LL1=1 (HELPED MANAGE PAIN LML)
or LL2=1 (HELPED WITH BREATHING LML)

or LL3=1 (HELPED WITH FEELINGS LML)
or LL6=1 (MADE MEDICAL DECISIONS FOR SP LML)), go to AC7A.

Otherwise, go to BOX AC7B.

AC7a	**cac7choredif**	C7 AC7AA LEVEL DIFFICULTY HELPING DO CHORES
	cac7shopdif	C7 AC7AB DIFFICULTY SHOPPING
	cac7rxdif	C7 AC7AC DIFFICULTY ORDERING MEDICINE
	cac7billsdif	C7 AC7AD DIFFICULTY BILLS BANKING
	cac7caredif	C7 AC7AE DIFFICULTY PERSONAL CARE
	cac7mobdif	C7 AC7AF DIFFICULTY GET AROUND HOME
	cac7drivdif	C7 AC7AG DIFFICULTY DRIVING
	cac7transdif	C7 AC7AH DIFFICULTY USING TRANSPORTATION
	cac7medsdif	C7 AC7AI DIFFICULTY MANAGING MEDICAL TASKS
	cac7exrcsdif	C7 AC7AJ DIFFICULTY MANAGING EXERCISE DIET
	cac7paindif	C7 AC7AK DIFFICULTY MANAGING PAIN
	cac7brethdif	C7 AC7AL DIFFICULTY MANAGING BREATHING
	cac7saddif	C7 AC7AM DIFFICULTY MANAGE ANXIETY SAD
	cac7decsdif	C7 AC7AN DIFFICULTY MAKE MED DECISIONS

DISPLAY INSTRUCTIONS:

If (CA1 = 1 (HELPED WITH CHORES EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Aa.

If (CA2= 1 (HELPED WITH SHOPPING EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Ab.

If CA3= 1 (HELPED ORDER MEDS), display AC7Ac.

If CA4=1 (HELPED WITH BILLS OR BANKING), display AC7Ad.

If (CA6 = 1 (HELPED WITH PERSONAL CARE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Ae.

If (CA7= 1 (HELPED GET AROUND HOME EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Af.

If (CA9= 1 (HELPED DRIVE EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Ag.

If (CA10= 1 (HELPED USE OTHER TRANSPORTATION EVERY DAY), 2 (MOST DAYS), 3 (SOME DAYS) or 4 (RARELY)), display AC7Ah.

If (CA11A=1 (HELPED TRACK MEDS) or CA11B=1 (HELPED WITH SHOTS OR INJECTIONS) or CA11C=1 (HELPED MANAGE MEDICAL TASKS) or CA11D=1 (HELPED WITH SKIN CARE)), display AC7Ai.

If (CA11A2A=1 (HELPED WITH EXERCISE) or CA11A2B=1 (HELPED WITH SPECIAL DIET)), display AC7Aj.

If LL1=1 (HELPED MANAGE PAIN LML), display AC7Ak.

If LL2=1 (HELPED WITH BREATHING LML), display AC7Al.

If LL3=1 (HELPED WITH FEELINGS LML), display AC7Am.

If LL6=1 (MADE MEDICAL DECISIONS FOR SP LML), display AC7An.

If CA11A=1 (HELPED TRACK MEDS), display "medications" in AC7Ai.

If CA11B=1 (HELPED WITH SHOTS OR INJECTIONS), display "shots or injections" in AC7Ai.

If CA11C=1 (HELPED MANAGE MEDICAL TASKS), display "medical tasks" in AC7Ai.
If CA11D=1 (HELPED WITH SKIN CARE), display "skin care" in AC7Ai.
If more than one task displayed in AC7Ai, display commas between each one and "and" before the last task display text.
If CA11A2A=1 (HELPED WITH EXERCISE), display "exercises" in AC7Aj.
If CA11A2B=1 (HELPED WITH SPECIAL DIET), display "special diet" in AC7Aj.
If more than one task displayed in AC7Aj, display "and" between the two task display texts.

If SP DECEASED flag=1 (YES), display "of {his/her} life" in stem question text.

Use "Same Question Stem" display.
If at first item (among those displayed), do not display question text in brackets.
Otherwise, display question text in brackets.

QUESTION TEXT:

{[}Next, for each task that you helped {SP} with in the last month {of {his/her} life}, please tell me if it was very, somewhat, a little or not at all difficult for you.{]}

{variable text [a-n]}

RESPONSE [1] a. doing chores around {his/her} home?
RESPONSE [2] b. shopping for {his/her} groceries or personal items?
RESPONSE [3] c. ordering {his/her} prescribed medicines?
RESPONSE [4] d. handling {his/her} bills and banking?
RESPONSE [5] e. providing personal care?

IF NEEDED: This includes help eating, showering, bathing, dressing or grooming, or using the toilet.

RESPONSE [6] f. helping {him/her} get around {his/her} home?

IF NEEDED: This includes getting out of bed, getting around inside, leaving home to go outside.

RESPONSE [7] g. driving {him/her} places?
RESPONSE [8] h. using transportation with {him/her}?
RESPONSE [9] i. managing {his/her} {medications} {shots or injections} {medical tasks} {skin care}?
RESPONSE [10] j. managing {his/her} {exercises} {special diet}?
RESPONSE[11]k. managing {his/her} pain in the last month of {his/her} life?
RESPONSE[12]l. managing {his/her} breathing in the last month of {his/her} life?
RESPONSE[13]m. managing {his/her} anxiety or sadness in the last month of {his/her} life?
RESPONSE[14]n. making medical decisions for {him/her} in the last month of {his/her} life?

CODES

1	VERY DIFFICULT
2	SOMEWHAT DIFFICULT
3	A LITTLE DIFFICULT
4	NOT AT ALL DIFFICULT
	REFUSED
	DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.
Display 'variable text' in the a-n sequence until all rows have been displayed.

BOX AC7B   BOX AC7B   NOT ON FILE

If (HC1 = 1 (COMMUNICATED WITH PROVIDERS) or HC5a = 1 (MADE APPTS FOR SP) or HC5b = 1 (LOGGED IN ONLINE FOR MED INFO) or HC5c = 1 (COORDINATED SP'S CARE) or HC6a = 1 (HELPED CHANGE/ADD

HEALTH INS) or HC6b = 1 (HANDLED OTHER HEALTH INS) or HC7 = 1 (HELPED AFTER OVERNIGHT STAY)), go to AC7B.

Otherwise, go to BOX AC8.

AC7b	**cac7talkdif**	C7 AC7BA LEVEL DIFFICULTY COMMUNICATE PROVIDERS
	cac7coorddif	C7 AC7BB DIFFICULTY COORDINATE MED CARE
	cac7insurdif	C7 AC7BC DIFFICULTY HANDLE HEALTH INSURANCE
	cac7hospdif	C7 AC7BD DIFFICULTY TRANSITION POST HOSP CARE

DISPLAY INSTRUCTIONS:
If HC1 = 1 (COMMUNICATED WITH PROVIDERS), display AC7Ba.
If HC5a = 1 (MADE APPTS FOR SP) or HC5b = 1 (LOGGED IN ONLINE FOR MED INFO) or HC5c = 1 (COORDINATED SP'S CARE), display AC7Bb.
If HC6a = 1 (HELPED CHANGE/ADD HEALTH INS) or HC6b = 1 (HANDLED OTHER HEALTH INS), display AC7Bc.
If HC7 = 1 (HELPED AFTER OVERNIGHT STAY)), display AC7Bd.

Use "Same Question Stem" display.
If at first item to be displayed and AC7Aa-n = NULL, do not display question text in brackets.
Otherwise, display question text in brackets.

If SP DECEASED flag=1 (YES) display "of {his/her} life".

QUESTION TEXT:
{[}Next, for each task that you helped {SP} with in the last year {of {his/her} life}, please tell me if it was very, somewhat, a little or not at all difficult for you.{]}

{variable text [a-d]}

RESPONSE [1] a. communicating with {his/her} medical providers?
RESPONSE [2] b. coordinating {his/her} health care?

IF NEEDED: This includes help with making appointments, checking results, and coordinating care across providers.

RESPONSE [3] c. handling {his/her} health insurance matters?
RESPONSE[4] d. transitioning {his/her} care after a hospital stay?

CODES

1	VERY DIFFICULT
2	SOMEWHAT DIFFICULT
3	A LITTLE DIFFICULT
4	NOT AT ALL DIFFICULT
	REFUSED
	DON'T KNOW

PROGRAMMER INSTRUCTIONS:
Array the responses and variable text columns in the panel.
Display 'variable text' in the a-d sequence until all rows have been displayed.

| **BOX AC8** | **BOX AC8** | NOT ON FILE |

If preloaded relationship of Caregiver to SP is 2 through 12, go to AC8.

Otherwise, go to BOX AC9PRE.

AC8

cac7fmlydisa   C7 AC8 LVL FMLY DISAGR OVER CARE

QUESTION TEXT:

In general, how much has your family disagreed over the details of (SP)'s care? Would you say very much, somewhat, or not so much?

CODES

1	VERY MUCH
2	SOMEWHAT
3	NOT SO MUCH
	REFUSED
	DON'T KNOW

AC8A

cac7careamt   C7 AC8A FAIR SHARE OF SP CARE

DISPLAY INSTRUCTIONS:

If SP DECEASED flag <> 1 (YES), display "do".
Otherwise, display "have done".

QUESTION TEXT:

Families sometimes share responsibility for caring for an older relative. In general, do you think you do more than your fair share, less than your fair share, or a fair amount?

CODES

1	MORE THAN FAIR SHARE
2	LESS THAN FAIR SHARE
3	FAIR AMOUNT
	REFUSED
	DON'T KNOW

BOX AC9PRE

BOX AC9PRE   NOT ON FILE

If SP DECEASED flag =1 (YES), go to SECTION SE – SUPPORT ENVIRONMENT.

Otherwise, go to AC9.

AC9

cac7exhaustd	C7 AC9A U ARE EXHAUSTED AT NIGHT
cac7toomuch	C7 AC9B CARE MORE THN CAN HANDLE
cac7notime	C7 AC9C U HAVE NO TIME FOR SELF
cac7uroutchg	C7 AC9D CARE ROUTINE THEN CHANGS

DISPLAY INSTRUCTIONS:

Use "Same Question Stem" display.

If at AC9a, do not display question text in brackets.

Otherwise, display question text in brackets.

QUESTION TEXT:

{[} Please listen to a few more statements and answer whether this describes your situation very much, somewhat, or not so much.{]}

{variable text [a-d]}

RESPONSE [1] a. You are exhausted when you go to bed at night.
RESPONSE [2] b. You have more things to do than you can handle.
RESPONSE [3] c. You don't have time for yourself.
RESPONSE [4] d. As soon as you get a routine going, {SP}'s needs change.

CODES

1	VERY MUCH
2	SOMEWHAT
3	NOT SO MUCH
	REFUSED
	DON'T KNOW

PROGRAMMER INSTRUCTIONS:

Array the responses and variable text columns in the panel.

Display 'variable text' in the a-d sequence until all rows have been displayed.

Go to Section SE - Support Environment.