Item S1. Patient survey

Chronic Kidney Disease Patient Survey

PART I. PATIENT ELIGIBILITY

- **S1.** What is your age?
 - 1. Under 18 years old [Terminate]
 - 2. 18-34 years old
 - 3. 35-44 years old
 - 4. 45-54 years old
 - 5. 55-64 years old
 - 6. 65-74 years old
 - 7. 75-84 years old
 - 8. 85 years or older
 - 9. Prefer not to answer [**Terminate**]
- **S2.** What is your level of comfort in reading and understanding the English language?
 - 1. Fluent / native language
 - 2. English is not my native language; I am very comfortable reading and understanding English
 - 3. English is not my native language; I am somewhat comfortable reading and understanding English
 - 4. English is not my native language; I am not at all comfortable reading and understanding English [Terminate]
- **S3.** What health conditions do you currently have, if any? *Please indicate all conditions you have been diagnosed with by a doctor.*
 - 1. Anemia
 - 1.1. Anemia due to chronic kidney disease (CKD)
 - 1.2. Anemia due to cancer
 - 1.3. Anemia due to nutrient deficiency (e.g., iron deficiency, vitamin deficiency)
 - 1.4. Other type of anemia (e.g., hemolytic anemia, aplastic anemia, sickle cell anemia)
 - 1.5. Don't know/ Not sure
 - 2. Cancer [Terminate]
 - 3. Cerebrovascular disease (e.g., stroke, transient ischemic attack)
 - 4. Chronic kidney disease (CKD) [Terminate if not selected]
 - 5. Chronic respiratory disease (e.g., asthma, chronic lung disease, chronic bronchitis, emphysema)
 - 6. Depression
 - 7. Diabetes
 - 8. Gout

- 9. Heart disease (e.g., cardiac arrhythmia, congestive heart failure, coronary artery disease, myocardial infarction, peripheral vascular disease [or bypass])
- 10. High cholesterol
- 11. Hyperkalemia (high potassium in blood)
- 12. Hypertension (high blood pressure)
- 13. Malnutrition
- 14. Thyroid problems (e.g., hypothyroidism, hyperthyroidism)
- 15. Other (please specify): _____
- 16. None
- **S4.** You indicated that you have been diagnosed with chronic kidney disease (CKD). Are you currently undergoing dialysis, on a regular basis? If so, please select the type of dialysis you are receiving below.
 - 1. Yes
 - 1.1. Hemodialysis (in-center)
 - 1.2. Hemodialysis (home)
 - 1.3. Peritoneal dialysis
 - 1.4. Don't know/ Not sure
 - 2. No
 - 3. Don't know/ Not sure [Terminate]
- **S5.** Have you had a kidney transplant or are you on the waitlist for a first kidney transplant?
 - 1. Yes, I have had at least one kidney transplant [**Terminate**]
 - 2. Yes, I am on the waitlist to have a first kidney transplant
 - 3 No
 - 4. Don't know/ Not sure [**Terminate**]

PART II. DISEASE CHARACTERISTICS

- **A1.** For how long have you been diagnosed with CKD? *Please enter the number of years since you were first told by a doctor that you had CKD.*
 - 1. Less than a year
 - 2. ____ year(s)
 - 3. Don't know/ Not sure

[ANEMIA PATIENTS ONLY]

- **A2.** For how long have you been diagnosed with anemia? *Please enter the number of years since you were first told by a doctor that you have anemia.*
 - 1. Less than a year
 - 2. _____ year(s)
 - 3. Don't know/ Not sure
- **A3.** Your doctor may have described your anemia as mild, moderate, or severe. If so, please indicate the severity level of your anemia.
 - 1. Mild
 - 2. Moderate
 - 3. Severe
 - 4. Don't know / Not sure
- **A4.** Have you received any treatment(s) to manage your anemia? *Please indicate the treatment(s) you currently receive and any treatment(s) you may have received in the past. If you received more than one treatment, please select all that apply.*

	Current anemia	Former anemia
	treatment(s)	treatment(s)
	(i.e., received within the	(i.e., not received in the
	last month)	last month)
1. Red blood cell transfusion		
2. Erythropoietin stimulating agents (ESAs; e.g., Procrit, Retacrit, Aranesp)		
3. Intravenous iron supplement (e.g., Venofer, Feraheme, Ferrlecit, Injectafer)		
4. Oral iron supplement		
5. Vitamin B12 supplement		
6. Folic acid supplement		
7. Other vitamin supplement (please specify)		
8. Dietary modification		
9. Other treatment (please specify)		
10. None		

[ANEMIA PATIENTS WITH AT LEAST ONE CURRENT ANEMIA TREATMENT ONLY]

- **A5.** Do you feel your current anemia treatment is helping to improve your symptoms?
 - 1. Yes
 - 2. No
 - 3. Don't know/ Not sure
- **A6.** How satisfied are you with your current anemia treatment(s)?
 - 1. I am extremely satisfied
 - 2. I am satisfied
 - 3. I am neither satisfied or dissatisfied
 - 4. I am dissatisfied
 - 5. I am extremely dissatisfied
- **A7.** What are the main reason(s) why you are satisfied with your current anemia treatment(s)? *Please select all that apply.*
 - 1. My symptoms have improved
 - 2. I have had no (or only mild) adverse reactions/side effects to treatment
 - 3. I feel my quality of life has improved
 - 4. My other health conditions have improved since starting my anemia treatment
 - 5. There have been no (or few) negative interactions with other medication(s) I am taking
 - 6. My treatment is convenient to take
 - 7. There are no or few monitoring requirements (e.g., regular lab tests) associated with my treatment
 - 8. My treatment does not cost me a lot of money (i.e., low out-of-pocket costs)
 - 9. Other (please specify):_____
- **A8.** What are the main reason(s) why you are dissatisfied with your current anemia treatment(s)? *Please select all that apply.*
 - 1. I have had mild adverse reactions/side effects to the treatment
 - 2. I have had severe adverse reactions/side effects to the treatment
 - 3. My treatment has not sufficiently improved my symptoms
 - 4. I feel my quality of life has gotten worse
 - 5. I have developed other health conditions as a result of treatment
 - 6. Other existing health conditions have gotten worse as a result of treatment
 - 7. My treatment has had negative interactions with other medication(s) I am taking
 - 8. My treatment is inconvenient or burdensome for me to take
 - 9. My treatment requires monitoring (e.g., regular lab tests) that is inconvenient or burdensome for me
 - 10. My treatment is expensive for me (i.e., high out-of-pocket costs)
 - 11. Other (please specify):

A9. Which type of e	erythropoietin stimulating agent (ESA) treatment are you currently receiving?
1. Injecti	on at home
	rree times per week (e.g., Monday, Wednesday, Friday)
1.2. Or	nce weekly
1.3. Or	nce every other week
1.4. Or	nce monthly
	on't know/ Not sure
· ·	on at a healthcare facility or dialysis center
	hree times per week (e.g., Monday, Wednesday, Friday)
	Once weekly
	Once every other week
	Once monthly
2.5. D	Oon't know/ Not sure
facility or dia	ow long does it take you to get ESA treatment when administered at a healthcare alysis center, from the moment you leave your residence to the moment you return? de all time for transportation, wait, and treatment at your healthcare provider.
1	hoursminutes
2. Don't l	know/ Not sure
_	ow often does a family member or friend accompany you for your ESA treatment istered at a healthcare facility or dialysis center? <i>Please select the answer that best ur situation</i> .
1. Alway	s (100% of the time)
•	y (~80% of the time)
•	(~60% of the time)
	imes (~40% of the time)
5. Rarely	(<20% of the time)
6. Never	(0% of the time)
7. Don't l	know/ Not sure
A12. On average, he	ow long does it take you to administer your ESA treatment at home?
1.	minutes
	know/ Not sure
	ow often does a family member or friend assist you with your ESA treatment at the select the answer that best describes your situation.
1. Alway	rs (100% of the time)
2. Usually	y (~80% of the time)
3. Often ((~60% of the time)
4. Someti	imes (~40% of the time)
5. Rarely	(<20% of the time)

- 6. Never (0% of the time)
- **A14.** If you were going to start a <u>new anemia treatment</u>, which type of treatment would you prefer, assuming the treatment works just as well?
 - 1. Oral (e.g., pill)
 - 1.1. Twice daily
 - 1.2. Once daily
 - 1.3. Three times per week (e.g., Monday, Wednesday, Friday)
 - 1.4. No preference
 - 2. Subcutaneous injection at home (i.e., injection under the skin)
 - 2.1. Three times per week (e.g., Monday, Wednesday, Friday)
 - 2.2. Once weekly
 - 2.3. Once every other week
 - 2.4. Once monthly
 - 2.5. No preference
 - 3. Intravenous injection at a healthcare facility (i.e., injection into a vein)
 - 3.1. Three times per week (e.g., Monday, Wednesday, Friday)
 - 3.2. Once weekly
 - 3.3. Once every other week
 - 3.4. Once monthly
 - 3.5. No preference
 - 4. Intravenous injection at a dialysis facility (i.e., injection into a vein)
 - 4.1. Three times per week (e.g., Monday, Wednesday, Friday)
 - 4.2. Once weekly
 - 4.3. Once every other week
 - 4.4. Once monthly
 - 4.5. No preference
 - 5. I don't have a preference for a type of treatment
 - 5.1. Once daily
 - 5.2. Three times per week (e.g., Monday, Wednesday, Friday)
 - 5.3. Once weekly
 - 5.4. No preference

[END OF ANEMIA QUESTIONS]

PART III. HEALTH-RELATED QUALITY OF LIFE

B1. Below is a list of statements that other people with your illness have said are important. Please select one number per line to indicate your response as it applies to the **past 7 days**.

	Not at all	A little bit	Somewhat	Quite a bit	Very
					much
Physical well-being					
1. I have a lack of energy					
2. I have nausea					
3. Because of my physical condition, I have trouble meeting the needs of my family					
4. I have pain					
5. I am bothered by the side effects of treatment					
6. I feel ill					
7. I am forced to spend time in bed					
Social/family well-being					
8. I feel close to my friends					
9. I get emotional support from my family					
10. I get support from my friends					
11. My family has accepted my illness					
12. I am satisfied with family communication about my illness					
13. I feel close to my partner (or the person who is my main support)					
Regardless of your current level of sexual activity please answer the following question. If you prefer not to answer it, please click this box.					
14. I am satisfied with my sex life					

	Not at all	A little bit	Somewhat	Quite a bit	Very
					much
Emotional well-being					
15. I feel sad					
16. I am satisfied with how I am coping with my illness					
17. I am losing hope in the fight against my illness					
18. I feel nervous					
19. I worry about dying					
20. I worry that my condition will get worse					
Functional well-being					
21. I am able to work (include work at home)					
22. My work (include work at home) is fulfilling					
23. I am able to enjoy life					
24. I have accepted my illness					
25. I am sleeping well					
26. I am enjoying the things I usually do for fun					
27. I am content with the quality of my life right now					
Additional concerns					
28. I feel fatigued					
29. I feel weak all over					
30. I feel listless ("washed out")					
31. I feel tired					
32. I have trouble <u>starting</u> things because I am tired					

	Not at all	A little bit	Somewhat	Quite a bit	Very
					much
33. I have trouble <u>finishing</u> things because I am tired					
34. I have energy					
35. I have trouble walking					
36. I am able to do my usual activities					
37. I need to sleep during the day					
38. I feel lightheaded (dizzy)					
39. I get headaches					
40. I have been short of breath					
41. I have pain in my chest					
42. I am too tired to eat					
43. I am interested in sex					
44. I am motivated to do my usual activities					
45. I need help doing my usual activities					
46. I am frustrated by being too tired to do the things I want to do					
47. I have to limit my social activity because I am tired					

PART IV. CARE RECEIVED

C1. During the <u>past 4 weeks</u>, have you received help or services from other people due to your health (e.g., help driving to medical visits, administering medical services in your home, performing chores or daily activities)? *If so, how many hours per week on average did you receive help or services? Please select all that apply.*

1. Spouse or partner	hours/week	
2. Parent or step-parent	hours/week	
3. Sibling or step-sibling	hours/week	
4. Child or step-child	hours/week	_
5. Aunt, uncle, or other relative	hours/week	_
6. Friend or neighbor	hours/week	_
7. Paid home care service or nurse	hours/week	
8. Other (please specify):	hours/week	_
9. Did not receive any help		_
2. Don't know/ Not sure		
PART V. EMPLOYMENT AND WORK PRODUCT	TIVITY LOSS	
D1. Are you currently employed (working for pay)?1. No2. Yes		
1. No		
1. No 2. Yes	ncluding today. ou miss from work because of your ways, times you went in late, left early,	, etc., because

D4.	During the past 7 1hou		<u>s,</u> hov	w ma	ny ho	ours (did y	ou ac	tuall	y woi	rk?		
D5.	were working? To days you accomple	hink ished i prod	abou l less blem	t day than s affe	vs you 1 you ected	ı wer woul your	e lim ld like wor	ited i e, or k onl	n the days y a lit	amo you o ttle, c	ount o could choos	r kind not do	oroductivity while you of work you could do, your work as carefully number. Choose a
		C	Consi	der o	only l	now r	nuch	heal	th pro	blen	<u>ns</u> aff	ected	
				proc	luctiv	ity <u>w</u>	<u>while</u>	you v	were_	work	ing.		
	Health problems nad no effect on												Health problems - completely prevented
	ny work	0	1	2	3	4	5	6	7	8	9	10	me from working
					SEI	LECT	AN	IUMI	BER				
D6.	daily activities, ot do, such as work of times you were lin accomplished less	her tl arour nited than	nan v nd the in th you	vork e hou e am wou	at a j use, s nount ld lik	ob? I hopp or ki e. If	By reging, of the office of th	gular childo activ	activare, vities oblen	vities exerc you is aff	, we t cising could ectea	mean ti g, study l do an l your d	ability to do your regular the usual activities you wing, etc. Think about d times you activities only a little, your activities a great
	Con	sider	only	how	muc	h <u>hea</u>	alth p	roble	ems_a	ffect	ed yo	our abil	ity
		to do	you	r reg	ular o	laily	activ	ities,	othe	r thar	ı wor	k at a j	ob.
ŀ	Health problems nad no effect on my daily activities	0	1	2	3	4	5	6	7	8	9	10	Health problems completely prevented me from doing my daily activities

SELECT A NUMBER

D7. Has your CKD contributed to making any of the following job-related decisions? *Please select all that apply. If you have increased or decreased the number of hours you work, please indicate by how many hours per week you increased or decreased your workload.*

Michalopoulos et al, Kidney Medicine,	"Patient and Care	Partner Burden in Ch	KD With and Without	t Anemia: A US-
Based Survey"				

- 1. Quit job or employment
- 2. Retired earlier than planned
- 3. Changed jobs or employers
- 4. Declined a job advancement (transfer or promotion)
- 5. Decreased the number of hours you work per week
 - 5.1. Decreased by _____ hours/week
- 6. Increased the number of hours you work per week
 - 6.1. Increased by _____ hours/week
- 7. Changed the shift you work
- 8. Taken a leave of absence
- 9. None
- 10. Don't know/ Not sure
- 11. Prefer not to answer

PART VI. DEMOGRAPHIC CHARACTERISTICS

- **E1.** What is your gender?
 - 1. Male
 - 2. Female
 - 3. Prefer not to answer
- **E2.** What is your ethnicity/race? *Please select all that apply.*
 - 1. African American or Black
 - 2. Asian or Pacific Islander
 - 3. Native American or Alaskan Native
 - 4. Hispanic or Latino
 - 5. White
 - 6. Other (please specify): _____
 - 7. Prefer not to answer
- **E3.** Please select your state of residence from the list below.

Item S2. Care-partner survey

Chronic Kidney Disease Caregiver Survey

PART I. CAREGIVER ELIGIBILITY

- **S1.** What is your age?
 - 1. Under 18 years old [Terminate]
 - 2. 18-34 years old
 - 3. 35-44 years old
 - 4. 45-54 years old
 - 5. 55-64 years old
 - 6. 65-74 years old
 - 7. 75-84 years old
 - 8. 85 years or older
 - 9. Prefer not to answer [**Terminate**]
- **S2.** What is your level of comfort in reading and understanding the English language?
 - 1. Fluent / native language
 - 2. English is not my native language; I am very comfortable reading and understanding English
 - 3. English is not my native language; I am somewhat comfortable reading and understanding English
 - 4. English is not my native language; I am not at all comfortable reading and understanding English [Terminate]
- **S3.** During the **past 4 weeks**, have you provided unpaid care or assistance to another adult who has chronic kidney disease (care recipient)?
 - 1. Yes
 - 2. No [Terminate]
- **S4.** Are you the primary caregiver for the care recipient, that is the person providing the greatest number of hours of care (excluding paid caregivers)?
 - 1. Yes
 - 2. No
 - 3. Don't know/ Not sure
- **S5.** What is the care recipient's age?
 - 1. Under 18 years old [Terminate]
 - 2. 18-34 years old
 - 3. 35-44 years old
 - 4. 45-54 years old
 - 5. 55-64 years old
 - 6. 65-74 years old

- 7. 75-84 years old
- 8. 85 years or older
- 9. Prefer not to answer [Terminate]
- **S6.** What health conditions does <u>the care recipient</u> currently have, if any? *Please indicate all conditions the care recipient has been diagnosed with by a doctor to the best of your knowledge.*
 - 1. Anemia
 - 1.1. Anemia due to chronic kidney disease (CKD)
 - 1.2. Anemia due to cancer
 - 1.3. Anemia due to nutrient deficiency (e.g., iron deficiency, vitamin deficiency)
 - 1.4. Other type of anemia (e.g., hemolytic anemia, aplastic anemia, sickle cell anemia)
 - 1.5. Don't know/ Not sure
 - 2. Cancer [Terminate]
 - 3. Cerebrovascular disease (e.g., stroke, transient ischemic attack)
 - 4. Chronic kidney disease (CKD) [Terminate if not selected]
 - 5. Chronic respiratory disease (e.g., asthma, chronic lung disease, chronic bronchitis, emphysema)
 - 6. Depression
 - 7. Diabetes
 - 8. Gout
 - 9. Heart disease (e.g., cardiac arrhythmia, congestive heart failure, coronary artery disease, myocardial infarction, peripheral vascular disease [or bypass])
 - 10. High cholesterol
 - 11. Hyperkalemia (high potassium in blood)
 - 12. Hypertension (high blood pressure)
 - 13. Malnutrition
 - 14. Thyroid problems (e.g., hypothyroidism, hyperthyroidism)
 - 15. Other (please specify):
 - 16. None
- **S7.** You indicated that the care recipient has been diagnosed with chronic kidney disease (CKD). Is the care recipient currently undergoing dialysis, on a regular basis? If so, please select the type of dialysis the care recipient is receiving below.
 - 1. Yes
 - 1.1. Hemodialysis (in-center)
 - 1.2. Hemodialysis (home)
 - 1.3. Peritoneal dialysis
 - 1.4. Don't know/ Not sure
 - 2. No
 - 3. Don't know/ Not sure [**Terminate**]
- **S8.** Has the care recipient undergone a kidney transplant or is he/she on the waitlist for a first kidney transplant?

- 1. Yes, the care recipient has had at least one kidney transplant [**Terminate**]
- 2. Yes, the care recipient is on the waitlist to have a first kidney transplant
- 3. No
- 4. Don't know/ Not sure [Terminate]

PART II. CHARACTERISTICS OF CARE RECIPIENT

- **A1.** For how long has the care recipient been diagnosed with CKD? *Please enter the number of years since a doctor first told the care recipient that he/she had CKD, to the best of your knowledge.*
 - 1. Less than a year
 - 2. ____ year(s)
 - 3. Don't know/ Not sure

[ANEMIA CARE RECIPIENTS ONLY]

- **A2.** For how long has the care recipient been diagnosed with anemia? *Please enter the number of years since the care recipient was first told by a doctor that he/she has anemia, to the best of your knowledge.*
 - 1. Less than a year
 - 2. ____ year(s)
 - 3. Don't know/ Not sure
- **A3.** The care recipient's doctor may have described his/her anemia as mild, moderate, or severe. If so, please indicate his/her anemia severity level.
 - 1. Mild
 - 2. Moderate
 - 3. Severe
 - 4. Don't know/ Not sure

A4. Has the care recipient received any treatment(s) to manage his/her **anemia?** *Please indicate the treatment(s) he/she currently receives and any treatment(s) he/she may have received in the past. If he/she received more than one treatment, please select all that apply.* [Selection boxes]

	received more than one treatment, pieds	Current anemia	Former anemia
		treatment(s) (i.e., received within the last month)	treatment(s) (i.e., not received within the last
1.	Red blood cell transfusion		month)
2.	Erythropoietin stimulating agents (ESAs; e.g., Procrit, Retacrit, Aranesp)		
3.	Intravenous iron supplement (e.g., Venofer, Feraheme, Ferrlecit, Injectafer)		
4.	Oral iron supplement		
5.	Vitamin B12 supplement		
6.	Folic acid supplement		
7.	Other vitamin supplement (please specify)		
8.	Dietary modification		
9.	Other treatment (please specify)		
10.	None		

- **A5.** If the care recipient were to start a <u>new anemia treatment</u>, which type of treatment would be the most convenient for you, assuming the treatment works just as well?
- 1. Oral (e.g., pill)
 - 1.1. Twice daily
 - 1.2. Once daily
 - 1.3. Three times per week (e.g., Monday, Wednesday, Friday)
 - 1.4. No preference
- 2. Subcutaneous injection at home (i.e., injection under the skin)
 - 2.1. Three times per week (e.g., Monday, Wednesday, Friday)
 - 2.2. Once weekly
 - 2.3. Once every other week
 - 2.4. Once monthly
 - 2.5. No preference
- 3. Intravenous injection at a healthcare facility (i.e., injection into a vein)
 - 3.1. Three times per week (e.g., Monday, Wednesday, Friday)
 - 3.2. Once weekly

3.3. Once every other week

3.4. Once monthly 3.5. No preference

4. Intravenous injection at a dialysis facility (i.e., injection into a vein) 4.1. Three times per week (e.g., Monday, Wednesday, Friday) 4.2. Once weekly 4.3. Once every other week 4.4. Once monthly 4.5. No preference 5. I don't have a preference for a type of treatment 5.1. Once daily 5.2. Three times per week (e.g., Monday, Wednesday, Friday) 5.3. Once weekly 5.4. No preference [END OF ANEMIA QUESTIONS] **A6.** What is the care recipient's gender? 1. Male 2. Female 3. Prefer not to answer **A7.** What is the care recipient's ethnicity/race? *Please select all that apply.* 1. African American or Black Asian or Pacific Islander 2. 3. Native American or Alaskan Native 4. Hispanic or Latino 5. White 6. Other (please specify):_____ Prefer not to answer PART III. CAREGIVING **B1.** What is your relationship with the care recipient? The care recipient is my: 1. Spouse or partner 2. Parent or step-parent 3. Sibling or step-sibling 4. Child or step-child 5. Aunt, uncle, or other relative 6. Friend or neighbor 7. Other (please specify): _____ 8. Prefer not to answer

B2. For appr	roximately how long have you provided care to the care recipient due to their CKD ?
1.	Less than a year
2.	year(s)
3.	Don't know/ Not sure
B3. Where	does the care recipient live?
1.	In a private home (owner occupied or rented)
	 1.1. Alone 1.2. With you 1.3. With another family member (including spouse or partner and step-family) 1.4. With a friend or other non-family member 1.5. With a full-time aid
	1.6. Other, specify
3.	In a retirement community / independent living group / senior housing complex In a care facility, such as a nursing home or assisted living facility Other (please specify):
	Don't know/ Not sure
	Prefer not to answer
recipies with da and fro	the past 4 weeks, on average, how many hours per week did you spend caring for the care nt? Please include all time you spent providing companionship, helping the care recipient sily routine or house chores, assisting with medical needs such as medical visits, driving to me the care recipient's home, or any other time spent caring for the care recipient. hours per week Don't know/ Not sure Prefer not to answer

PART IV. HEALTH-RELATED QUALITY OF LIFE

- **C1.** What health conditions do you currently have, if any? *Please indicate all conditions you have (including those not related to caregiving and those that began before you started caregiving), whether or not it has been formally diagnosed by a doctor.*
 - 1. Alzheimer's disease or dementia
 - 2. Anxiety
 - 3. Cancer (including leukemia, lymphoma, metastatic solid tumor)
 - 4. Cerebrovascular disease (e.g., stroke, transient ischemic attack)
 - 5. Chronic fatigue syndrome
 - 6. Chronic respiratory disease (e.g., asthma, chronic lung disease, chronic bronchitis, emphysema)
 - 7. Depression
 - 8. Diabetes
 - 9. Gastrointestinal symptoms (e.g., nausea, vomiting, diarrhea)
 - 10. Headache(s) or migraine(s)
 - 11. Heart disease (e.g., cardiac arrhythmia, congestive heart failure, coronary heart disease, myocardial infarction, peripheral vascular disease or bypass)
 - 12. Hypertension (high blood pressure)
 - 13. Renal (kidney) disease
 - 14. Sleep disturbance(s) or insomnia
 - 15. Substantial weight loss or gain (e.g., \geq 10 pounds)
 - 16. Other, (please specify):
 - 17. None
 - 18. Prefer not to answer

C2. Below is a list of statements related to how you feel about providing care to the care recipient.

We are asking you for information about your <u>present</u> situation. The following statements often refer to the care you provide. This may be any kind of support up to nursing care. *Please select the best description of your present situation*.

Statement	Strongly agree	Agree	Disagree	Strongly disagree
1. My life satisfaction has suffered				
because of the care.				
2. I often feel physically exhausted.				
3. From time to time I wish I could "run				
away" from the situation I am in.				
4. Sometimes I don't really feel like "myself" as before.				
5. Since I have been a caregiver my				
financial situation has decreased.				
6. My health is affected by the care				
situation.				
7. The care takes a lot of my own				
strength.				
8. I feel torn between the demands of my				
environment (such as family) and the				
demands of the care				
9. I am worried about my future because				
of the care I give.				
10. My relationships with other family				
members, relatives, friends and				
acquaintances are suffering as a result of				
the care.				

PART V. EMPLOYMENT AND WORK PRODUCTIVITY LOSS

The next questions are about the past 7 days, not including today.

D1. Are you currently employed (working for pay)?

No
 Yes

	on si ou m	ck de	iys, t	imes	you v	vent i	in lat	e, lefi				e of caregiving? <i>Include</i> ause of caregiving. Do
D3. During the past 7 such as vacation, 1hou	holid										oecaus	e of any other reason,
D4. During the <u>past 7</u> 1hou		s , ho	w ma	ıny ho	ours (did y	ou ac	tually	y woi	·k?		
	about l less ing af	days than fecte ffect	you you d you ed yo nside	were would ir wo	limi d like rk on ork a y hov	ted in e, or a uly a grea w mu	the days ; little, at dea	amou you c choo l.	ent or ould ose a ving	kina not a low i	l of wo lo your umbe	rk you could do, days r work as carefully as
Caregiving had no effect on my work	0	1	2	3 SEI	4 LECT	5 T A N	6 IUMI	7 BER	8	9	10	Caregiving - completely prevented me from working
such as work arou you were limited i	nan w und th in the ke. If	ork and the hore amount of the hore of the	nt a jo puse, punt o egivin	ob? B shopp or kin ng afj	y reg ping, d of c fected	rular chila activi d you	activ lcare ities y r acti	ities, , exer vou co ivities	we n cisin ould s only	nean ng, sti do an v a lin	the usindying id time	o your regular daily ual activities you do, , etc. Think about times es you accomplished less oose a low number.

Consider only how much caregiving affected your ability

to do your regular daily activities, other than work at a job.

Caregiving had no effect on my daily	-											Caregiving
activities	0	1	2	3	4	5	6	7	8	9	10	 completely prevented me from doing my daily
												activities

SELECT A NUMBER

- **D7.** Have you made any of the following job-related decisions <u>due to caregiving</u> for the care recipient? If you have made more than one decision, please select all that apply. If you have increased or decreased the number of hours you work due to caregiving, please indicate by how many hours per week you increased or decreased your workload.
 - 1. Quit job or employment
 - 2. Retired earlier than planned
 - 3. Changed jobs or employers
 - 4. Declined a job advancement (transfer or promotion)
 - 5. Decreased the number of hours you work per week
 - 5.1. Decreased by _____ hours/week
 - 6. Increased the number of hours you work per week
 - 6.1. Increased by _____ hours/week
 - 7. Changed the shift you work
 - 8. Taken a leave of absence
 - 9. None
 - 10. Don't know/ Not sure
 - 11. Prefer not to answer

PART VI. DEMOGRAPHIC CHARACTERISTICS

- **E1.** What is your gender?
 - 1. Male
 - 2. Female
 - 3. Prefer not to answer
- **E2.** What is your ethnicity/race? *Please select all that apply.*
 - 1. African American or Black
 - 2. Asian or Pacific Islander

- 3. Native American or Alaskan Native
- 4. Hispanic or Latino
- 5. White
- 6. Other (please specify):
- 7. Prefer not to answer

E3. Please select your state of residence from the list below.

Table S1. ESA characteristics¹

	Anemia Cohort	Dialysis dependent	Non-dialysis dependent		
Number of patients receiving ESAs, N	N = 54	N=42	N=12		
Type and frequency of ESA					
treatment, n (%)	11 (20 10/)	0 (10 00()	2 (25 00/)		
Injection at home	11 (20.4%)	8 (19.0%)	3 (25.0%)		
Three times per week	3 (27.3%)	2 (25.0%)	1 (33.3%)		
Once weekly	2 (18.2%)	2 (25.0%)	0 (0.0%)		
Once every other week	5 (45.5%)	3 (37.5%)	2 (66.7%)		
Once monthly	1 (9.1%)	1 (12.5%)	0 (0.0%)		
Unknown	0 (0.0%)	0 (0.0%)	0 (0.0%)		
Intravenous injection at a healthcare facility or dialysis center	43 (79.6%)	34 (81.0%)	9 (75.0%)		
Three times per week	4 (9.3%)	4 (11.8%)	0 (0.0%)		
Once weekly	8 (18.6%)	7 (20.6%)	1 (11.1%)		
Once every other week	11 (25.6%)	8 (23.5%)	3 (33.3%)		
Once monthly	12 (27.9%)	7 (20.6%)	5 (55.6%)		
Unknown	8 (18.6%)	8 (23.5%)	0 (0.0%)		
ESA injection at home	, ,	, , , ,	, ,		
Duration of ESA treatment	0.5 17.0 [5.0]	11 1 . 10 0 [5 0]	20 - 20[20]		
(minutes), 2 mean \pm SD [median]	$9.5 \pm 17.8 [5.0]$	$11.1 \pm 19.8 [5.0]$	$3.0 \pm 2.8 [3.0]$		
Unknown	1 (9.1%)	0 (0.0%)	1 (33.3%)		
Help from a family member or frien	nd to				
administer ESA at home ² , n (%)		4.470.00	0. (0. 0)		
Always (100% of the time)	4 (36.4%)	4 (50.0%)	0 (0.0%)		
Usually (~80% of the time)	2 (18.2%)	1 (12.5%)	1 (33.3%)		
Often (~60% of the time)	0 (0.0%)	0 (0.0%)	0 (0.0%)		
Sometimes (~40% of the time)	0 (0.0%)	0 (0.0%)	0 (0.0%)		
Rarely (<20% of the time)	1 (9.1%)	1 (12.5%)	0 (0.0%)		
Never (0% of the time)	4 (36.4%)	2 (25.0%)	2 (66.7%)		
ESA intravenous injection at					
healthcare facility or dialysis center					
Duration of ESA treatment (hours) ^{3,4} , mean ± SD [median]	$2.0 \pm 1.8 [1.5]$	$2.3 \pm 2.0 [1.4]$	$1.4 \pm 0.5 [1.5]$		
Unknown	13 (30.2%)	12 (35.3%)	1 (11.1%)		
Family member or friend	13 (30.270)	12 (33.370)	1 (11.170)		
accompanying at ESA treatment visit ⁴ , n (%)					
Always (100% of the time)	7 (16.3%)	3 (8.8%)	4 (44.4%)		
Usually (~80% of the time)	2 (4.7%)	2 (5.9%)	0 (0.0%)		
Often (~60% of the time)	1 (2.3%)	1 (2.9%)	0 (0.0%)		
Sometimes (~40% of the time)	0 (0.0%)	0 (0.0%)	0 (0.0%)		
Rarely (<20% of the time)	5 (11.6%)	4 (11.8%)	1 (11.1%)		
Never (0% of the time)	28 (65.1%)	24 (70.6%)	4 (44.4%)		

Abbreviations: ESA: erythropoiesis stimulating agent, SD: standard deviation

- 1. Characteristics were measured at the time of data collection for patients who indicated being diagnosed with anemia and currently treated with an ESA.
- 2. Evaluated among patients who indicated currently receiving ESA treatment at home (N=11).
- 3. Duration of ESA treatment at a healthcare facility or dialysis center was defined as from the moment a patient leaves their residence to the moment they return, including all time for transportation, wait, and treatment by the healthcare provider.
- 4. Evaluated among patients who indicated currently receiving ESA treatment at a healthcare facility or dialysis center (N=43).

Table S2. Care received by patients¹

	Anem	ia Cohort	Anemia-free Cohort			
Number of patients, N	N	= 190	N = 220			
Number of hours of care received per week ² , mean ± SD [median]	14.2 ±	26.3 [4.0]	11.3 ±	24.2 [2.0]		
Number of care-partners, n (%)						
0	70	(36.8%)	99	(45.0%)		
1	48	(25.3%)	52	(23.6%)		
2	33	(17.4%)	28	(12.7%)		
3+	31	(16.3%)	32	(14.5%)		
Unknown	8	(4.2%)	8	(3.7%)		
Relationship to care-partners ³ , n (%)						
Spouse or partner	67	(35.3%)	86	(39.1%)		
Parent or step-parent	17	(8.9%)	13	(5.9%)		
Sibling or step-sibling	11	(5.8%)	10	(4.5%)		
Child or step-child	37	(19.5%)	41	(18.6%)		
Aunt, uncle, or other relative	6	(3.2%)	8	(3.6%)		
Friend or neighbor	25	(13.2%)	16	(7.3%)		
Paid home care service or nurse	16	(8.4%)	14	(6.4%)		
Other	5	(2.6%)	3	(1.4%)		

Abbreviations: SD: standard deviation

- 1. Care received was measured at the time of data collection, based on recollection from the past 4 weeks.
- 2. Care includes both paid and unpaid care.
- 3. Patients could select more than one option (not mutually exclusive).

Table S3. Care received, anemia-related characteristics, HRQoL, and employment and work productivity among patients stratified by dialysis status¹

		Dialysis d	ependei	Non-dialysis dependent				
	Ane	mia Cohort	Anemia-free Cohort		Anemia Cohort		Anemia-free Cohort	
Number of patients, N		N = 80		N = 110]	N = 110	N	V = 110
Care received ²								
Number of hours of care received per week, mean ± SD	20.0	. 24 0 [0 5]	15.0	. 20 5 15 01	10.0	. 10 0 [2 0]	(7.	15 5 10 01
[median]	20.0	\pm 34.0 [8.5]	15.9	\pm 28.7 [5.0]	10.0	\pm 18.0 [3.0]	0.7 ±	17.5 [0.0]
Number of care-partners, n (%)								
0	22	(27.5%)	33	(30.0%)	48	(43.6%)	66	(60.0%)
1	20	(25.0%)	32	(29.1%)	28	(25.5%)	20	(18.2%)
2	21	(26.3%)	16	(14.5%)	12	(10.9%)	12	(10.9%)
3+	13	(16.3%)	24	(21.8%)	18	(16.4%)	8	(7.3%)
Unknown	4	(5.0%)	5	(4.5%)	4	(3.6%)	3	(2.8%)
Relationship to care-partners ³ , n (%)								
Spouse or partner	33	(41.3%)	55	(50.0%)	34	(30.9%)	31	(28.2%)
Parent or step-parent	9	(11.3%)	11	(10.0%)	8	(7.3%)	2	(1.8%)
Sibling or step-sibling	5	(6.3%)	7	(6.4%)	6	(5.5%)	3	(2.7%)
Child or step-child	20	(25.0%)	28	(25.5%)	17	(15.5%)	13	(11.8%)
Aunt, uncle, or other relative	1	(1.3%)	7	(6.4%)	5	(4.5%)	1	(0.9%)
Friend or neighbor	12	(15.0%)	7	(6.4%)	13	(11.8%)	9	(8.2%)
Paid home care service or nurse	10	(12.5%)	12	(10.9%)	6	(5.5%)	2	(1.8%)
Other ⁴	1	(1.3%)	0	(0.0%)	4	(3.6%)	3	(2.7%)
Did not receive any help	22	(27.5%)	33	(30.0%)	48	(43.6%)	66	(60.0%)
Anemia-related characteristics ⁵								
Preferred route of administration ⁶								
Oral	32	(40.0%)		_	51	(46.4%)		_
Twice daily	9	(28.1%)		_	0	(0.0%)		_
Once daily	10	(31.3%)		_	32	(61.5%)		_
Three times per week	6	(18.8%)		_	5	(4.6%)		_
No preference	7	(21.9%)		_	14	(26.9%)		_
Subcutaneous injection at home	7	(8.8%)		_	7	(6.4%)		_
Three times per week	4	(57.1%)		_	0	(0.0%)		_

Once weekly	2	(28.6%)	_	5	(71.4%)	_
Once every other week	0	(0.0%)	_	1	(14.3%)	_
Once monthly	0	(0.0%)	_	1	(14.3%)	_
No preference	1	(14.3%)	_	0	(0.0%)	_
Intravenous injection at a healthcare facility	7	(8.8%)	_	8	(7.3%)	_
Three times per week	1	(14.3%)	_	1	(12.5%)	_
Once weekly	2	(28.6%)	_	3	(37.5%)	_
Once every other week	1	(14.3%)	_	1	(12.5%)	_
Once monthly	3	(42.9%)	_	3	(37.5%)	_
No preference	0	(0.0%)	_	0	(0.0%)	_
Intravenous injection at a dialysis facility ⁷	14	(17.5%)	_	0	(0.0%)	_
Three times per week	3	(21.4%)	_		_	_
Once weekly	4	(28.6%)	_		_	_
Once every other week	1	(7.1%)	_		_	_
Once monthly	2	(14.3%)	_		_	_
No preference	4	(28.6%)	_		_	_
No preference for a type of treatment	17	(21.3%)	_	21	(19.1%)	_
No preference for a specific schedule	0	(0.0%)	_	1	(4.8%)	_
Once daily	0	(0.0%)	_	0	(0.0%)	_
Three times per week	7	(41.2%)	_	9	(42.9%)	_
Once weekly	10	(58.8%)	_	11	(52.4%)	
HRQoL						
FACT-An score ⁸ , mean ± SD [median]	108.4	± 31.7 [108.0]	$114.4 \pm 37.0 $ [112.5]	111.3 :	± 33.0 [109.8]	$128.7 \pm 30.8 [134.5]$
FACT-G score	64.5 :	± 18.6 [65.5]	$68.4 \pm 21.0 [69.0]$	66.8	± 18.8 [66.5]	$73.6 \pm 17.9 [76.0]$
Physical well-being	16.9	$\pm 6.3 [17.0]$	$17.2 \pm 7.2 [18.5]$	19.0	± 5.9 [20.0]	22.4 ± 5.2 [24.0]
Social/family well-being	17.9	± 6.4 [19.0]	19.6 ± 6.6 [21.0]	17.4	± 7.2 [17.5]	17.6 ± 6.8 [18.5]
Emotional well-being	15.9	$\pm 6.5 [18.0]$	$15.9 \pm 6.1 [17.0]$	15.9	± 5.3 [17.0]	$15.5 \pm 4.7 [16.0]$
Functional well-being	13.7	± 6.1 [14.0]	15.6 ± 6.8 [16.0]	14.5	± 6.3 [14.0]	18.1 ± 5.7 [19.0]
Anemia score	44.0	± 15.7 [42.5]	46.1 ± 17.9 [45.0]	44.5	± 16.1 [43.5]	55.1 ± 15.2 [56.5]
Employment and Work Productivity						
Currently employed, n (%)	29	(36.3%)	31 (28.2%)	26	(23.6%)	47 (42.7%)
WPAI-SHP ⁹ , % ± SD [median]						
Activity impairment due to health	56.3	± 27.8 [60.0]	50.4 ± 30.5 [50.0]	48.8	± 28.1 [50.0]	28.0 ± 28.0 [20.0]
Overall work impairment due to health	55.7	± 32.1 [61.8]	$59.8 \pm 28.9 \ [60.0]$	33.2	± 29.9 [24.6]	21.4 ± 26.4 [10.0]
Work time missed due to health (absenteeism)		± 29.2 [7.7]	$27.8 \pm 28.3 [21.1]$		± 12.7 [0.0]	$5.5 \pm 18.6 [0.0]$
Impairment while working due to health (presenteeism)		± 30.9 [40.0]	$48.5 \pm 26.8 [50.0]$		± 27.5 [20.0]	$17.8 \pm 21.4 [10.0]$
impairment while working due to neutri (presenteelsin)		= = = []	20.0 [20.0]	20.0	[_0.0]	o = - [10.0]

Had at least one job-related decision due to health, n (%)	61	(76.3%)	66	(60.0%)	39	(35.5%)	40	(36.4%)
Job-related decisions due to health ³ , n (%)								
Retired earlier than planned	22	(27.5%)	33	(30.0%)	17	(15.5%)	17	(15.5%)
Decreased the number of hours worked per week	24	(30.0%)	17	(15.5%)	14	(12.7%)	14	(12.7%)
Quit job or employment	25	(31.3%)	28	(25.5%)	12	(10.9%)	7	(6.4%)
Took a leave of absence	11	(13.8%)	15	(13.6%)	8	(7.3%)	3	(2.7%)
Changed jobs or employers	11	(13.8%)	11	(10.0%)	6	(5.5%)	7	(6.4%)
Declined a job advancement (transfer or promotion)	8	(10.0%)	8	(7.3%)	3	(2.7%)	3	(2.7%)
Changed shift	5	(6.3%)	9	(8.2%)	4	(3.6%)	2	(1.8%)
Increased the number of hours worked per week	0	(0.0%)	4	(3.6%)	0	(0.0%)	1	(0.9%)
None	18	(22.5%)	44	(40.0%)	67	(60.9%)	64	(58.2%)
Unknown	1	(1.3%)	0	(0.0%)	4	(3.6%)	6	(5.5%)

Abbreviations: FACT - An: functional assessment of cancer therapy - Anemia; FACT-G: functional assessment of cancer therapy - general; HRQoL: health-related quality of life; SD: standard deviation; WPAI-SHP: work productivity and activity impairment - specific health problem

- 1. Outcomes were measured at the time of data collection.
- 2. Care received includes paid and unpaid care based on recollection from the past 4 weeks at the time of data collection.
- 3. Patients could select more than one option (not mutually exclusive).
- 4. Patients reported receiving help from other individuals: paid professional (non-healthcare) (n=6), former spouse/partner (n=1).
- 5. Anemia-related characteristics were measured for respondents who indicated having anemia.
- 6. Preferred frequency of administration was asked only to the subset of patients who indicated the particular route of administration was preferred.
- 7. Intravenous injection at a dialysis facility was displayed only to patients who indicated receiving dialysis (N=80).
- 8. The FACT-An questionnaire considers HRQoL during the past 7 days at the time of data collection. The FACT-An score is the sum of the FACT-G score and the anemia subscale score. The total FACT-G score is the sum of the physical well-being, social/family well-being, emotional well-being, and functional well-being subscales, scores can range from 0 to 28. For emotional well-being subscale, scores can range from 0 to 24. For anemia subscale, scores can range from 0 to 80. For FACT-G, scores can range from 0 to 108 and for FACT-An, 0 to 188. For all scales, a higher score indicates higher QoL.
- 9. The WPAI-SHP considers impairment during the past 7 days at the time of data collection. Outcomes are expressed as impairment percentages, with higher numbers indicating greater impairment and less productivity. Activity impairment refers to the impact of health problems on the ability to complete daily activities and was measured among all patients. Overall work impairment, presenteeism, and absenteeism refer to the impact of health problems on the ability to work and were measured among employed patients.

Table S4. Care provided, anemia-related characteristics, HRQoL, and employment and work productivity among care-partners stratified by dialysis status¹

	Dialysis dependent			Non-dialysis dependent			
	Anemi	a Cohort	Anemia-free Cohort	Ane	mia Cohort		mia-free ohort
Number of care-partners, N	N	= 68	N = 80	N = 42		N	T = 68
Caregiving characteristics							
Care-partner lives with the care recipient, n (%)	32 ((47.1%)	45 (56.3%)	24	(57.1%)	45 (66.2%)
Number of hours per week spent caring for the care recipient (overall) ² , mean \pm SD [median]	31.8 ± 3	35.0 [24.0]	41.0 ± 42.6 [25.0]	36.7	± 37.3 [20.0]	34.8 ±	38.9 [20.0]
Number of hours per week spent caring if living with the care recipient	54.0 ± 4	1.5 [40.0]	$47.8 \pm 43.1 \ [30.0]$	50.7	± 45.0 [52.0]	37.4 ±	39.9 [24.0]
Anemia-related characteristics ³							
Preferred route of administration ⁴							
Oral	26 ((38.2%)	_	25	(59.5%)	_	-
Twice daily	8 ((30.8%)	_	2	(8.0%)	_	-
Once daily	11 ((42.3%)	_	10	(40.0%)	_	-
Three times per week	1 ((3.8%)	_	5	(20.0%)	_	-
No preference	6 ((23.1%)	_	8	(32.0%)	-	-
Subcutaneous injection at home	20 ((29.4%)	_	7	(16.7%)	-	-
Three times per week	4 ((20.0%)	_	2	(28.6%)	-	-
Once weekly	12 ((60.0%)	_	4	(57.1%)	-	-
Once every other week	2 ((10.0%)	_	0	(0.0%)	_	-
Once monthly	0 ((0.0%)	_	1	(14.3%)	-	-
No preference	2 ((10.0%)	_	0	(0.0%)	-	-
Intravenous injection at a healthcare facility	4 ((5.9%)	_	2	(4.8%)	-	-
Three times per week	0 ((.0%)	_	0	(0.0%)	-	-
Once weekly	1 ((25.0%)	_	0	(0.0%)	-	-
Once every other week	2 ((50.0%)	_	1	(50.0%)	-	-
Once monthly	1 ((25.0%)	_	0	(0.0%)	-	-
No preference	0 ((0.0%)	_	1	(50.0%)	-	-
Intravenous injection at a dialysis facility ⁵	9 ((13.2%)	_	0	(0.0%)	-	-
Three times per week	4 ((44.4%)	_		_	-	-
Once weekly	3 ((33.3%)	_		_	-	-

			1	
Once every other week	0 (0.0%)	_	_	_
Once monthly	2 (22.2%)	_	_	_
No preference	0 (0.0%)	_	_	_
No preference for a type of treatment	9 (13.2%)	_	8 (19.0%)	_
No preference for a specific schedule	5 (55.6%)	_	6 (75.0%)	_
Once daily	2 (22.2%)	_	0 (0.0%)	_
Three times per week	1 (11.1%)	_	0 (0.0%)	_
Once weekly	1 (11.1%)	_	2 (25.0%)	_
HRQoL				
BSFC-s score (overall) ⁶ , mean ± SD [median]	17.3 ± 6.5 [18.0]	$16.3 \pm 6.0 [16.0]$	15.4 ± 7.5 [15.5]	14.4 ± 7.2 [14.0]
Low burden, n (%)	2 (2.9%)	3 (3.8%)	4 (9.5%)	8 (11.8%)
Moderate burden, n (%)	16 (23.5%)	23 (28.8%)	12 (28.6%)	27 (39.7%)
Severe to very severe burden, n (%)	50 (73.5%)	54 (67.5%)	26 (61.9%)	33 (48.5%)
Care-partners living with the care recipient	,	, ,		, ,
$BSFC$ -s score ³ , mean $\pm SD$ [median]	$17.9 \pm 6.2 [18.0]$	16.4 ± 5.9 [17.0]	16.1 ± 7.3 [16.0]	14.5 ± 7.1 [14.5]
Low burden, n (%)	1 (3.1%)	2 (4.4%)	2 (8.7%)	6 (14.3%)
Moderate burden, n (%)	6 (18.8%)	13 (28.9%)	4 (17.4%)	15 (35.7%)
Severe to very severe burden, n (%)	25 (78.1%)	30 (66.7%)	17 (73.9%)	21 (50.0%)
Employment and Work Productivity				
Currently employed, n (%)	45 (66.2%)	42 (52.5%)	22 (52.4%)	32 (47.1%)
WPAI-CG (overall) ⁷ , $\% \pm SD$ [median]				
Activity impairment due to caregiving	$54.0 \pm 28.9 \ [60.0]$	46.0 ± 27.0 [50.0]	41.0 ± 26.9 [45.0]	$39.3 \pm 28.9 [40.0]$
Overall work impairment due to caregiving	$54.7 \pm 27.1 [55.6]$	$42.0 \pm 28.5 \ [38.6]$	$32.8 \pm 25.7 [30.0]$	$38.8 \pm 33.1 [40.0]$
Work time missed due to caregiving (absenteeism)	$26.3 \pm 27.4 [17.7]$	16.0 ± 24.2 [8.1]	$2.9 \pm 5.7 [0.0]$	$13.2 \pm 22.9 \ [0.0]$
Impairment while working due to caregiving (presenteeism)	41.0 ± 25.7 [50.0]	33.4 ± 25.3 [30.0]	31.5 ± 25.0 [30.0]	$33.0 \pm 28.2 [35.0]$
Had at least one job-related decision due to caregiving, n (%)	54 (79.4%)	52 (65.0%)	22 (52.4%)	27 (39.7%)
Job-related decisions due to caregiving ⁸ , n (%)				
Retired earlier than planned	7 (10.3%)	10 (12.5%)	2 (4.8%)	8 (11.8%)
Decreased the number of hours worked per week	24 (35.3%)	18 (22.5%)	11 (26.2%)	8 (11.8%)
Quit job or employment	12 (17.6%)	12 (15.0%)	6 (14.3%)	5 (7.4%)
Took a leave of absence	22 (32.4%)	7 (8.8%)	1 (2.4%)	3 (4.4%)
Changed jobs or employers	15 (22.1%)	10 (12.5%)	6 (14.3%)	4 (5.9%)
Declined a job advancement (transfer or promotion)	11 (16.2%)	10 (12.5%)	2 (4.8%)	2 (2.9%)
Changed shift	18 (26.5%)	13 (16.3%)	3 (7.1%)	4 (5.9%)
Increased the number of hours worked per week	4 (5.9%)	4 (5.0%)	4 (9.5%)	1 (1.5%)
None	14 (20.6%)	27 (33.8%)	19 (45.2%)	38 (55.9%)
Unknown	0 (0.0%)	1 (1.3%)	1 (2.4%)	3 (4.4%)

Abbreviations: BSFC-s: burden scale for family caregivers - short version; HRQoL: health-related quality of life; SD: standard deviation; WPAI-CG: work productivity and activity impairment - caregiver

- 1. Outcomes were measured at the time of data collection.
- 2. Measured at the time of data collection, based on recollection from the past 4 weeks.
- 3. Anemia-related characteristics were measured for respondents who indicated having anemia.
- 4. Preferred frequency of administration was asked only to the subset of care-partners who indicated the particular route of administration was preferred.
- 5. Intravenous injection at a dialysis facility was displayed only to care-partners who indicated providing care to a care recipient receiving dialysis (N=68).
- 6. BSFC-s score ranges from 0 to 30 points and higher scores indicate greater care-partner burden. Scores ranging from 0 to 4 indicate a degree of subjective burden ranging from none to low, with no increased risk of physical psychosomatic complaints. Scores ranging from 5 to 14 indicate a moderate degree of subjective burden, with an increased risk of physical psychosomatic complaints. Scores ranging 15 to 30 indicate a severe to very severe degree of subjective burden and a very much increased risk of physical psychosomatic complaints.
- 7. The WPAI-CG considers impairment during the past 7 days at the time of data collection. Outcomes are expressed as impairment percentages, with higher numbers indicating greater impairment and less productivity. Activity impairment refers to the impact of caregiving on the ability to complete daily activities and was measured among all care-partners. Overall work impairment, presenteeism, and absenteeism refer to the impact of caregiving on the ability to work and were measured among employed care-partners.
- 8. Care-partners could select more than one option (not mutually exclusive).