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Purpose: To document the patient's level of physical activity post-transplant. The Physical Activity Questionnaire will be administered via phone interview to patients who are adult at the time of the 8th anniversary of their first liver transplant. As was previously defined in the LTD, an adult is anyone at least 16 years old. Person(s) Responsible: DCC personnel. Source(s) of Information: The patient. This questionnaire is conducted via phone interview by trained personnel at General Instructions: the Data Coordinating Center to assess the patient's leisure and occupational physical activity and level of difficulty performing activities of daily living. Completion Log: 1) Data Collector ID - Record the data collector ID in the space provided on the form cover sheet. Record the two-digit data coordinating center identification code number (04) and the data collector's three initials (first letter of first, middle, and last names). 2) Data Collection Date – Record the date (month/day/year) on which the form is considered to be accurate and complete. 3) The remaining completion log entries are for data entry use only.

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PATIENT ID

This is the identification number assigned to the patient upon entry into the LTD. Record the data coordinating center identification code number (04) before the hyphen and the assigned 7 digit patient identification number after the hyphen. The patient ID should be recorded at the top of each page of the form in the space provided.

NAME

Record the patient's full name (first name, last name, and middle initial) in the space provided on the form.

TODAY'S DATE

Record the date (month/day/year) on which the phone interview was conducted.

1. WORK ACTIVITY

Document the patient's work activity during the past 12-month period. Record the "month to month" duration of the year for which the information is collected. For each job/position document the corresponding information. Complete one job/position description entirely before moving on to the next.

<u>For Example</u>: If the phone interview is conducted in March, ask the following question, "How many months in the past year have you worked from last **April** to this **March**?"

Job Name – Ask the patient to list all the jobs/positions he/she held during the past year that lasted more than one month and record names of those jobs/positions. If the patient was unemployed, disabled, retired, a homemaker, or a student during all or part of the year, record as such. All 12 months of the past year should be accounted for. A Job or position such as disabled, homemaker, retired, student, or unemployed should be recorded for months during which no other job was identified.

Job Code – Record the job code number that best corresponds to the job/position described by the patient.

Walk or Bicycle to/from Work - Document whether the patient usually walked or rode a bicycle to and from work. Record the average number of minutes per day that the patient walked or rode a bike. If the patient was disabled, homemaker, retired, student, or unemployed during all or part of the year, record "0" for that job/position (the question is not applicable).

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Job Schedule - Record the average job schedule for each job/position listed. The job schedule is the average number of months per year, days per week, and hours per day that the patient worked at each job. If the patient was disabled, homemaker, retired, student, or unemployed during all or part of the year, record the number of months in that position, and then record "5" day week and "8" hour day. Account for all of the time in a typical 40-hour work week. If the patient worked part-time on a job (i.e., less than 40 hours per week) record the other types of jobs/positions the patient held for the time remaining in a typical 40-hour work week.

Hours Spent Sitting - Record the typical number of hours per day that the patient sat while on a job out of the total number of hours/day reported working on that job.

<u>For Example</u>: Ask the patient, "In your job as a janitor, you mentioned that you worked an average of 6 hours per day. In a typical day in your job as a janitor, how many of those 6 hours would I find you sitting?"

If the patient was disabled, homemaker, retired, student, or unemployed during all or part of the year, document the number of hours the patient sat during the typical 8-hour work day.

<u>For Example</u>: Ask the patient, "During a typical 8-hour day at home, how much of those 8 hours would I find you sitting?"

Job Activities When Not Sitting – Ask the patient to describe the job activities that he/she engaged in when not sitting at the job/position and check the appropriate category.

<u>For Example</u>: Ask the patient, "You mentioned that you usually sit for 1 of your 6 hours in your job as a janitor. What are you doing the other 5 hours in your job when not sitting?"

If the patient was disabled, homemaker, retired, student, or unemployed during all or part of the year, document the non-sitting activity level during the typical work day.

<u>For Example</u>: Ask the patient, "You mentioned that you usually sit for 6 out of your 8 hours at home. What activities are you doing the other 2 hours when not sitting?"

Listen carefully to the job activities described by the patient. Use the category descriptions listed below the question to determine the category that best describes the patient's reported activity level. Category A (light activity) includes job activities that involve sitting, standing still, and short distance walking, such as walking around an office, house, operating room, or classroom. Category B (moderate activity) includes job activities that require more effort similar to that of continuous walking, such as walking outside or walking as part of a janitorial duty. Category C (heavy activity) contains activities that are not on the list, choose the most appropriate category. If the patient describes activities that straddle two categories, ask the patient which activities were engaged in most frequently and check the appropriate category. If activities of equal frequency straddle two categories, check the more active category.

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2. MODIFIED ACTIVITY QUESTIONNAIRE

Document all the activities that the patient engaged in over the past year. Obtain this information by reading aloud to the patient the list of 36 activities. Instruct the patient to identify all activities from this list in which he/she had engaged on at least 10 different occasions over the past year. Circle the activities for which the patient gave a positive response. At the end of the list, the further probe for any other activities not listed that the patient engaged in over the past year. For each activity the patient engaged in, record the required information in the table below the activity list. Complete information collection for one activity entirely before beginning with the next activity.

Activity Code/Specify - Based on the patient's positive responses to the activity list, record the activity code number and activity name.

Jan to Dec – Place a check the appropriate column to indicate the month(s) in which the activity was performed. Begin with 12 months prior and work forward in time.

<u>For Example</u>: Ask the patient, "You mentioned that you participated in karate over the past year. Starting from last April 1996 until the present, during which months did you do karate?"

* Note: If someone replies that they have performed the activity throughout the entire year, remind them of what that means: "You performed this activity during ALL 12 months over the past year from last April 1996 until now?"

Average number of times per month – Record the average number of times per month that the patient engaged in the activity.

<u>For Example</u>: Ask the patient, "You said that you participated in karate during X,Y and Z months over this past year. During a typical month that you participated in karate, what is the average number of times per month that you would usually perform karate?"

This is the only question that may require calculations. If the patient replies "about 3 times per week," the interviewer should multiply that number by 4 to convert it to "per month." Verify by asking the patient, "Three times per week is an average of 12 times per month. Does this sound correct?" It is critical that both the answer and the time frame (per month) be repeated to the patient. The following scenario often occurs: The patient simply replies "3 times" to the times per month question. When the interviewer verifies with "3 times per month," the patient responds... "Oh no, I meant 3 times per week." In other words, be careful that the number that is recorded in the "Times per Month" column does in fact reflect times per month.

Average number of minutes each time - Record the average number of minutes each time the patient engaged in the activity.

<u>For Example</u>: Ask the patient, "During a typical time when you are doing karate, what is the average number of minutes that it usually lasts?" Again, repeat the answer before recording it in the appropriate column. Only those activities that were performed for a minimum of 10 minutes are to be recorded.

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* Note: Walking or biking in the leisure activity section does **not** include walking or biking to and from work. Walking or biking to and from work is to be documented in the occupational activity section only.

2.2 ON A TYPICAL DAY DURING NON-WORKING HOURS, HOW MANY HOURS DO YOU SPEND:

Record the number of hours per day, during typical non-work hours, that the patient engaged in 1) watching TV and videos; 2) computer activities; 3) sleeping/napping; and 4) sitting and reading books/magazines. Record "0" if the patient did not engage in the activity.

2.3 OVER THIS PAST YEAR, HAVE YOU SPENT MORE THAN ONE WEEK CONFINED TO A BED OR CHAIR AS A RESULT OF AN INJURY, ILLNESS, OR SURGERY?

Check "Yes" or "No" to indicate whether or not the patient spent more than one week confined to a bed or chair during the past 12 months as a result of an injury, illness, or surgery.

<u>If Yes</u>: Record the number of weeks during the past 12 months that the patient was confined to a bed or chair. If the patient was confined to a bed or a chair for less than one week, record "0".

2.4 DID YOU EVER COMPETE IN AN INDIVIDUAL OR TEAM SPORT (NOT INCLUDING ANY TIME SPENT IN SPORTS PERFORMED DURING SCHOOL PHYSICAL EDUCATION CLASSES)?

Check "Yes" or "No" to indicate whether the patient competed in individual or team sports at anytime during his/her lifetime.

<u>If Yes</u>: Record the total number of years that the patient participated in competitive sports. If the patient participated in a sport for only part of a year, record as "1" year. The number of years should reflect the total number of years throughout the patient's lifetime (not just he past 12 months).

* Note: If the patient participated in 3 sports at the same time for 2 full years, the total number of years of participation would be "2" not "6". This answer should reflect the actual number of years in the patient's lifetime that he/she was involved in individual or team sports.

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3. ACTIVITIES OF DAILY LIVING

The following are questions about activities that may be done in a typical day.

3.1 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE TAKING CARE OF YOURSELF, THAT IS EATING, DRESSING, OR BATHING?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.2 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE MOVING IN AND OUT OF BED OR CHAIR?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.3 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE WALKING INDOORS, SUCH AS AROUND YOUR HOME?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.4 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE WALKING SEVERAL BLOCKS?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.5 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE WALKING ONE BLOCK OR CLIMBING ONE FLIGHT OF STAIRS?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.6 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE DOING WORK AROUND THE HOUSE SUCH AS CLEANING, LIGHT YARD WORK, HOME MAINTENANCE?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

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3.7 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE DOING ERRANDS, SUCH AS GROCERY SHOPPING?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.8 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE DRIVING A CAR OR USING PUBLIC TRANSPORTATION?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

3.9 DURING THE PAST MONTH, HOW MUCH PHYSICAL DIFFICULTY DID YOU HAVE DOING VIGOROUS ACTIVITIES SUCH AS RUNNING, LIFTING HEAVY OBJECTS OR PARTICIPATING IN STRENUOUS SPORTS?

If the patient engaged in the activity, check the appropriate item to indicate whether the patient did it with no difficulty, some difficulty, or much difficulty. If the patient did not engage in the activity, check whether it was not done due to health problems or other reasons.

4. DO YOU OWN A COMPUTER?

Check "Yes" or "No to indicate whether the patient owns a computer and has internet access.

* REMEMBER: NEVER OFFER ANY ANSWERS, GUESSES, OR SUGGESTIONS TO ANY ITEMS ON THE PA QUESTIONNAIRE, OTHERWISE THE RESULTS MAY BE BIASED.