

**NIDDK Liver Transplantation Database
MANUAL OF OPERATIONS (MOOP) DEFINITION**

FORM: QP (QUALITY OF LIFE: PEDIATRIC)

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Purpose: To document the pediatric (< age 16) patient's quality of life following the initial liver transplant. The QP form will be sent annually to the pediatric patient's parent or guardian on the anniversary of the initial liver transplant.

Person(s) Responsible: Parent, guardian, or primary caregiver of the child.

Source(s) of Information: Parent, guardian, or primary caregiver of the child.

General Instructions: The Quality of Life Form for children is meant to be filled out by the parent, guardian, or other primary caretaker of the transplant patient. This form is **not** to be given to the child to complete.

The QP form is self-explanatory and the parent/caretaker should be encouraged to fill out the form on his/her own. Help may be provided by the LTD coordinator if the parent/caretaker is unable to understand the questions because of educational, cultural, or language difficulties. In these situations the LTD coordinator or interpreter can read the questions to the parent/caretaker and record the answers. If the parent/caretaker does not want to answer a question, he/she should put a mark through that question on the questionnaire.

For continuity, the same parent should complete this form at each timepoint. Even for the older pediatric population, the parent should be the one completing this form. The obvious drawback here is that the child and parent may answer the subjective questions differently.

Once the form is filled out, the parent or guardian should return the form to the DCC or appropriate clinical center in the pre-addressed, postage-paid envelope that is provided. Upon receipt of the form, the LTD clinical center coordinator or DCC staff member should check that the form was completed correctly and completely. If the form has not been returned after two months, the clinical coordinator or a DCC staff member will make a follow-up call and this form may be administered by phone at that time.

The answers to all questions on the form should be kept confidential and none revealed to the physicians or nurses responsible for the patient's care, or even to the principal investigator for the Liver Transplantation Database. This confidentiality should be maintained even for answers that might seem to have an impact on the child's care and development.

Completion Log:

- 1) Form Received Date – Record the date (month/day/year) that the form is received by mail, or the date that the interview is completed by phone.
- 2) The remaining completion log entries are for data entry use only.

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The Quality of Life Form for children is comprised of several different scales of assessment.

Two of the scales, the social and the gross motor assessments, are subtests taken from the Scales of Independent Behavior (SIB). The social scale is, in part, an indicator of how well the child is able to do in various social systems (family, friends and community). The gross motor assessment tests 17 large muscle skills from early development through more mature motor activities. At first glance, both the social and gross motor assessment sections may appear to group children into categories which are inappropriate for their age; however it is imperative to point out that each child should be tested according to developmental rather than chronological age group. The parent should be instructed to begin answering questions in the developmental bracket that fits the child's ability and answer all questions within that grouping as well as continue on into the next age group (if that is appropriate) and do the same.

The format of both of these is relatively structured to facilitate easy administration and objective assessment.

The SIB Scales have several practical qualities which make them appealing to the LTD: (1) a novice can administer both of the subtests, (2) they are brief, both tests taking perhaps twenty minutes to complete and (3) they are one of the few behavioral testing tools that lends itself to the entire age range of the pediatric group (infancy to age 16).

Results of the SIB can be reported as percentiles, standard scores, normal curve equivalents or age equivalents. The SIB was originally designed to assess skills needed to function independently. It also includes a scale for identifying problem or maladaptive behaviors (they are not currently included in our Quality of Life Form, however).

Two of the other sections of this Quality of Life Form are taken from the Rand Experiment: How Well Has Your Child Been and Your Child's Health. They are both brief and straightforward in their content.